

A thesis submitted in partial fulfilment of
the requirements for the degree of
Doctor of Philosophy

2010. *Does anybody like being disabled? A critical exploration of impairment, identity, media and everyday experience in a disabling society.* PhD thesis. Queen Margaret University.

Accessed from:

<http://etheses.qmu.ac.uk/258/>

Repository Use Policy

The full-text may be used and/or reproduced, and given to third parties for personal research or study, educational or not-for-profit purposes providing that:

- The full-text is not changed in any way
- A full bibliographic reference is made
- A hyperlink is given to the original metadata page in eResearch

eResearch policies on access and re-use can be viewed on our Policies page:
<http://eresearch.qmu.ac.uk/policies.html>

<http://etheses.qmu.ac.uk>

DOES ANYBODY LIKE BEING DISABLED?

**A CRITICAL EXPLORATION OF
IMPAIRMENT, IDENTITY, MEDIA
AND EVERYDAY EXPERIENCE
IN A DISABLING SOCIETY**

**A thesis submitted in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy**

QUEEN MARGARET UNIVERSITY

2010

Abstract

I offer a critical exploration of tensions experienced by disabled people in the construction of positive identities in everyday contexts in which self-understanding is shaped both by social structural relations of inequality and unique individual experience. The empirical evidence I use to develop and support my thesis involves data I have generated using a variety of data collection tools, through a series of interviews, conversations and observations carried out with sixteen disabled people across Scotland and England. I argue that while certain barriers to participation in ordinary community life may be being removed, perceptions of impairment as something ‘wrong’ with the bodies of disabled people remain embedded in dominant disability discourse. There is a structural purpose underlying the continued representation of impairment as misfortune, involving the ascription of a negative role – the disabled role – to those whose bodily configurations pose a challenge to requirements of conformity. Drawing on insights generated in my research, and building on an idea originally proposed by John Swain and Sally French in 2000, I have developed a clarified affirmative model of disability. This I intend as a tool to be used by people with impairments in making sense of the disabling social relations they encounter in everyday contexts, to be used alongside the social model in gaining knowledge to unsettle mainstream assumptions which can only recognise impairment as personal tragedy.

Keywords:

Disability, Impairment, Social Model, Affirmative Model, Identity, Media, Everyday Life

Acknowledgements

I want to take this opportunity to thank the sixteen disabled people who gave up their time and let me into their confidence in order to carry out my PhD research. Unless people asked me to use their real names, names in this list are disguised. Each person knows who they are: Ali, Anne, Ash, Ben, Brian, Charles, Hazel, Helen, Jennie, Kevin, Lola, Mary, Rose, Roshni, Sarah, and Surinder.

I would also like to thank my PhD supervisors in the School of Arts and Social Sciences at Queen Margaret University for their advice and supportive criticism: Dr Mark Gillham, Dr Richard Butt and John Hughes.

Special thanks must be given to Eleanor Coner who gave me invaluable help in transcribing interviews.

Finally I want to thank my wife Maggie, for her indefatigable patience and constant support.

Contents

Introduction	p.1
Chapter 1: Disability, Self and Identity	p.6
Chapter 2: What's the Use of Disability Identity?	p.39
Chapter 3: Methodology	p.50
Chapter 4: Subject Positioning	p.79
Chapter 5: Disability as Role	p. 116
Chapter 6: Media Representations	p.159
Chapter 7: Disability in Everyday Life	p.200
Conclusion	p.254
References	p.260

Appendix A: Introductory Letter

Appendix B: Email Extracts

Appendix C: Interview Guide

Appendix D: Themes arising from the first series of interviews

Published Material

Cameron, C. (2007) 'Breve storia del movimento delle persone disabili nel Regno Unito'. *Rivista Sperimentale di Freniatria*. Vol. CXXXI N.2/2007 pp.83-99

Cameron, C. (2007) 'Whose Problem? Disability narratives and available identities'. *Community Development Journal*. Vol 42 No 4 October 2007 pp.501-511.

Cameron, C. (2008) 'Further towards an affirmation model'. In Campbell, T. Fontes, F. Hemingway, L. Soorenian, A. and Till, C. (Eds.) *Disability Studies: Emerging Insights and Perspectives*. Leeds: The Disability Press

Cameron, C. (2009) 'Tragic but brave or just crips with chips? Songs and their lyrics in the Disability Arts Movement in Britain'. *Popular Music*. Vol. 28/3. Pp. 381-396

Introduction

I offer here a critical exploration of tensions experienced by disabled people in the construction of positive identities in everyday contexts in which self-understanding is shaped both by social structural relations of inequality and unique individual experience. Following Pierre Bourdieu (1990) I contend that everyday life is constrained by social structures and is at the same time an active process of production which transforms social structures. Regarding identity as a project to be worked at rather than as a fixed characteristic, and borrowing from Margaret Archer, I would suggest that explaining what disabled people do involves reference to their 'subjective and reflective formulation of personal projects – in the light of their objective circumstances' (Archer, 2003:5). As John Swain and I have argued, for example, in 'coming out' and claiming identity as disabled, people with impairments not only subvert dominant disability discourses but 'change the very meaning of disability' (Swain and Cameron, 1999:77).

My purpose as a disabled researcher is to do more, however, than just develop critical awareness around these matters. Drawing on the insights of the sixteen disabled people I have interviewed in my research, and building on an idea originally proposed by John Swain and Sally French in 2000, I have developed a clarified affirmative model of disability. This I intend as a tool to be used by people with impairments in making sense of the disabling social relations they encounter in everyday life contexts; to be used among other tools in gaining knowledge to unsettle and challenge mainstream assumptions which can only recognise impairment as personal tragedy. I regard this as part of a wider political and cultural struggle through which people with impairments are increasingly able to come to understand and name disability as oppression and to rename themselves as people who have a right to respect on their own terms.

In order to explain my meaning by the term 'tensions' I draw on a statement made by Donna Reeve:

Someone may be disabled by a flight of steps or by being given information in an inaccessible format – these are examples of the structural dimensions of disability which restrict activity. On the other hand, psycho-emotional dimensions of disability would include being stared at or patronised by strangers, actions which can leave disabled people feeling worthless and ashamed, and may end up preventing them from participating in society as effectively as physically inaccessible environments (Reeve, 2006:96).

When I speak of tensions I mean something like the almost constant underlying state of uncertainty experienced by many disabled people in relation to how they are being perceived and received by others around them; something like the easily-awakened awareness of the likelihood that they are being watched and found wanting, or seen as deficient, incompetent and unfortunate. Tensions are experienced by disabled people in the knowledge that other people avoid contact with them because they are disabled, as if somehow their impairment was contagious or as if being seen with them would be a cause of embarrassment. They are experienced in the discomfort that being pitied or spoken down to can arouse, a sensation that can be experienced anytime any place, in the company of family members or others barely known. They can be experienced in terms of being unsure about whether to be forthright about access requirements or whether to keep silent and pretend there is nothing wrong for fear of being considered a nuisance. Tensions are involved in disabled people's uncertainty about whether to be assertive in owning their own needs and opinions or whether just to shut up and put up with second-rate treatment for fear of upsetting people or being regarded as needy and demanding. Tensions are there when complete strangers tell disabled people that they are an inspiration just for getting on with things everybody else does all the time; and in situations where they know they are being watched as if they are freak show exhibits. Tensions can involve a more or less constant sense of guardedness or wariness about how to respond within interactions, leading perhaps either to compliance with the expectations and wishes of others or to the development of a hardened public face which presents an indifference to the way one is treated. All of these can have a profound impact on the ways disabled people feel about themselves.

Tensions are experienced when encountering what Cal Montgomery has described as:

those little acts of degradation to which others subject us... those little reminders that we need to know our place in the world (Montgomery, 2006:unpaged).

As Montgomery comments:

Every few hours I run up against people who feel free to remind me that I'm their inferior and that I should conform to whatever they've decided 'people like [me]' are supposed to be like (Montgomery, 2006: unpaged).

The empirical evidence I use to develop and support my thesis involves data I have generated using a variety of data collection tools, through a series of interviews, conversations and observations carried out with sixteen disabled people from Fraserburgh to Brighton, with Perthshire, Glasgow, Edinburgh, Bonnyrigg, Whitley Bay, Liverpool,

Coventry, Northampton and London in-between. During the first series I carried out semi-structured interviews in which I asked participants to reflect upon their own experiences and about the way they related to the idea of disability. The second series involved unstructured interviews in which participants talked about their perceptions of media representations of disability as resources to draw on in making sense of their own experience. In the final series I made as-it-happens observations of a variety of mundane activities in which participants engaged as part of everyday life.

In order to gain a wide divergence of responses in my data I chose as participants disabled people in their twenties, thirties, forties and fifties; people from isolated rural and cosmopolitan urban environments; people from LGBT and straight communities; people from BME and white communities; people with and without religious faith; people with physical, sensory, emotional and intellectual impairments; people who have been disabled since childhood and people who have become disabled in adulthood; and, finally, people who said they feel very positive about being who they are, people who said they see disability just as part of life but not as something to go on about, and people who said they hate the disability experience. My research is about disabled people's own perceptions of their own situations. It is about how disabled people regard themselves in the light of ways in which dominant non-disabled culture expects them to regard themselves.

Taking into account Andy Rickell's observation in *Disability Now* that only six per cent of disabled people identify with the social model of disability, I cannot claim that my participant group is quantitatively representative (Rickell, 2009). Five out of the sixteen people I interviewed are emotionally and intellectually committed to the social model. But as my purpose is consciously political I do not regard this as problematic. I start from a position that no circumstance contains its own conditions of existence and that everything is relational. Underpinning this research is a critical perspective which attempts to dig beneath the surface of accounts in order to throw new light on the ways in which social structural relations are experienced, resisted and transformed by disabled individuals.

I have adopted a hybrid approach in my use of theoretical sources, incorporating a wide range of sociologists and psychologists whose most significant (if only) shared characteristic is, perhaps, that they are 'critical'. For example, I draw on Pierre Bourdieu, Erich Fromm, Sheldon Stryker, Antonio Gramsci, Paulo Friere, Henri Lefebvre, Fran Martin, Conrad Lodziak, Alfred Schutz, Norbert Elias, Patchen Markell, John Fiske, Zygmund Bauman, Anthony Giddens, Judith Butler, C. Wright Mills. In terms of Disability Studies theorists, I make use of John Swain, Sally French, Mike Oliver, Colin Barnes, Mary Johnson, Allan

Sutherland, Richard Rieser and Micheline Mason, Rosemary Thomson, Donna Reeve, Carol Thomas, and Paul Darke, among others. I have drawn insight from Media Studies writers including Tony Wilson, Karen Dill, Jean Baudrillard, Paul Taylor and Jan Harris, Richard Dyer, Gareth Palmer, Neil Postman and Richard Hoggart.

I use the social model of disability as the ontological and epistemological basis for my research production and for my discussion (Priestley, 1997). This means that from the outset I make a fundamental distinction between the concepts of *impairment* and *disability*. I regard impairment as a material, fixed characteristic of human beings. The reality of being disabled that I describe is the everyday embodied experience of living with impairment in a disabling society. I regard disability as an oppressive social relationship, as ‘something imposed on top of our impairments’ (UPIAS, 1976:14).

Throughout my research I have been guided by the core principles characteristic of an emancipatory disability research paradigm: surrendering claims to objectivity through overt political commitment to the struggle of disabled people for self-emancipation; carrying out research that will be of some practical benefit to the self-empowerment of disabled people; being accountable in my research production to research participants; giving voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers. I have, furthermore, adopted a plurality of data collection methods (Priestley, 1997:91).

I will also, however, be focussing a critical gaze upon the social model in order to examine its adequacy as an explanatory tool for the description and analysis of the everyday experience of living with impairment in a disabling society. There is no necessary contradiction here and parallels can be observed within other areas of sociological discussion: e.g. feminist perspectives are brought to bear in critiquing and developing feminist theory (Butler, 1990).

I am aware that my presence and outlook has significantly impacted upon the shape and outcomes of this project, but do not regard this as a limitation. As a disabled person who has spent the majority of my life wrestling with disability identity issues at a personal level (Swain and Cameron, 1999) my motivations for carrying out this research have been both personal and political. Having been involved as an activist in the disabled people’s movement for almost two decades, I regard my research as arising out of and feeding back into the struggle of the movement (Watson, 2004). I intend that this study will challenge routine oppression and play a role in facilitating the personal liberation of disabled people

(Moore, Beazley and Maelzer, 1998).

My opening chapter involves a discussion and evaluation of existing literature as it relates to my thesis. My second chapter considers disability identity and includes a personal account of my own experience in relation to this. In my third chapter I describe the research process. In chapters four and five I discuss themes arising from the first series of interviews on participants' subject positioning. Chapter six considers participants' reflections on media representations as resources for making sense of the disability experience. In my final chapter I describe and analyse observations I made of participants' engagement in the midst of everyday life. I finish with a short conclusion.

My clarified affirmative model definitions are grounded within and emerge from my analysis of participants' accounts of their own experiences. At the present time there have been no major research projects engaging with the affirmative model, which remains a tentative proposition rather than a tested hypothesis. It is in the clarification and evaluation of the affirmative model that I aim to have made an original contribution to knowledge.

Chapter 1: Disability, Self and Identity

The medical model as ideology

In that it distorts our perceptions of humanity and relationships between human individuals, Micheline Mason identifies the influence of the medical model of disability as having a role in the oppression of *all* people, both disabled and non-disabled. The removal of people identified as having significant impairments from the mainstream of social life, as well as being oppressive to people with impairments themselves, has rendered impairment a subject of fear and embarrassment that non-disabled people feel unsure about and uncomfortable dealing with (Rieser and Mason, 1992:78). Through a process involving the medicalisation of society (Zola, 2005:51), forms of social knowledge have been imposed which suggest that aberration from socially valued norms of physical embodiment is exceptional rather than an ordinary part of human experience and is best addressed by professionals. Individualising professional practices remove people with impairments from their social contexts and communicate a number of related propositions:

You are deficient.

You are the problem.

I, the professionalised servicer, am the answer.

You are not the answer.

Your peers are not the answer.

The political, social and economic environment is not the answer.

(McKnight, J. 2005)

A message is communicated to those identified as unimpaired that disability is an individual problem, but not *their* problem. When impairment is removed from sight, it becomes an object of pity, of comedy, of charity, of fear or hostility, to be dealt with by others elsewhere. Normality is highly prized. The 'normal' person, described by Erich Fromm as 'the person who is able to fulfil the social role he has been given and to work in the fashion that contemporary society requires of him' (Fromm, 2001:119), is allowed to escape the angst of being reminded of his own vulnerability and temporality that encounter with people with impairments on a regular basis would involve. This is covered over by the daily routine of his activities, by the assurance and approval he finds in his private or social relations, by success in business, by any number of distractions, by 'having fun', 'making contacts', 'going places' (Fromm, 2001:115).

As Roger Silverstone comments:

Our everyday lives are the expression, in their taken-for-grantedness, as well as (in popular culture) their self-consciousness, of our capacity to hold a line against the generalised anxiety and the threat of chaos that is a *sine qua non* of social life. In this sense everyday life is a continuous achievement (Silverstone, 1999:165).

But while the regularity of everyday life and the distraction provided by absorption in its trivial details may offer comfort and security, it does not offer an escape from alienation. Normality, like the bourgeois individualism Henri Lefebvre writes of:

implies the dreary, ludicrous repetition of individuals who are curiously similar in their way of being themselves and of keeping themselves to themselves, in their speech, their gestures, their everyday habits (Lefebvre, 2008:152).

To cite Fromm again, whereas the normal person is pleased to be her own individual, the things that she thinks and says are very often just the same things that everyone else is thinking and saying:

We neglect the role of the anonymous authorities like public opinion and ‘common sense’, which are so powerful because of our readiness to conform to the expectations that everyone has about ourselves and our equally profound fear of being different (Fromm, 2001:91).

Being normal involves a process of learning to want to act in the ways that society requires one to act. This is not to say that normality is experienced as being either totally pleasurable or completely alienating. For most people it contains elements of both: a sense of well-being as well as a limitation of possibilities. As Brian Longhurst notes, people find extraordinary pleasures in their ordinary lives as well as mundanity and restriction. They enjoy their ordinary lives as well as hating parts of them (Longhurst, 2007:20). While there may exist a sense that things are not all they should or could be, there is at the same time a reluctance to give up the security that normality offers.

Impairment as inferiority

That impairment and disability are regarded in terms of inferiority can be identified in the cultural dominance of the medical or individual model of disability, expressed in the World Health Organisation’s 1981 International Classification of Impairments, Disabilities and Handicaps (ICIDH). This makes the following distinctions:

Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function

Disability: any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being

(WHO, 1981)

The terms *loss*, *abnormality*, *restriction* or *lack of ability* are heavily-laden with cultural meaning and indicate a perception of impairment and disability as characteristics of individual deficit. Disability is regarded as emerging as a consequence of impairment. Cure, care, and therapy are regarded as appropriate social responses to what is identified as a personal problem (Edwards, 2005:15).

The medical model is materialised in everyday practice through the myriad of behaviours, decisions, and interactions taking place in the contexts in which disabled people experience their lives. It is put into practice through the ways that services are delivered, plans are made, words are spoken, texts are read. It is embodied in gestures and assumptions, thoughts spoken and unspoken, hopes and expectations held, in conversations people have with each other and in inner conversations they have with themselves. Because it is a dominant model of disability, reflecting the view of the world of the non-disabled, its character as a model, as a way of looking at things, is almost always overlooked. It is considered common sense to regard impairment as misfortune.

Disabled critics, however, argue that the medical model represents an ideological position and is a particular manifestation of what Michael Oliver has termed 'the ideology of normality' (Oliver, 1996:104). This is to use the term *ideology* in the sense proposed by Antonio Gramsci, as having a material existence embodied in the social practices of individuals and in the institutions and organisations within which these social practices take place (Gramsci, A. 1996). Normality, Oliver argues, is a construct imposed on a reality where there is only difference (1996:88). Lennard Davis points out that the term *normal*, meaning *conforming to, not deviating or differing from the common type or standard, regular, usual*, only enters the English language around 1840 (Davis, 1995:24). Disability emerges as a social category with the advent of industrialisation, the rapid growth of manufacturing towns and cities, and the arising need for a standard, replaceable able-bodied worker who can meet the production requirements of the factory system. People with impairments, excluded from employment on the grounds of being unable to keep pace with these requirements, found themselves removed from the mainstream of economic and

community life and placed in a range of institutional settings. Involved here are processes signifying the systematic individualisation and medicalisation of the body and the mind (Barnes, C. 1997:19). Individual abnormality only appears when normality becomes a social requirement. Impairment only becomes identified as abnormality when marked as such by procedures of surveillance.

Rather than being a physical characteristic of individuals, my position is that disability is a relationship experienced by people with impairments in a social world that has systematically excluded them from ordinary life. This is most clearly expressed in the social model proposed by the Union of the Physically Impaired Against Segregation in 1976, which defines disability as:

the disadvantage or restriction of activity caused by a social organisation which takes no or little account of people with physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1976:14).

Ideology working

Ideology has to work both extensively and intensively: to maintain its authority by spreading its own preferred ways of thinking and to penetrate into the innermost areas of consciousness (Fiske, 1993:31). I

In order to maintain the illusion that that things as they happen to be are more or less the way they should be, it is necessary to constantly produce and reproduce images and narratives that legitimise versions of reality favourable to the powerful. As Gramsci has observed, while common sense may be the site in which dominant ideology is given texture it is also the site of resistance and challenge to ideology (Gramsci, A. 1996). Human beings are not passive subjects, prepared to believe anything, but reflective agents, able to make their own sense of the world in which they find themselves.

In developing my thesis I want to focus particularly on ways in which the personal tragedy model of disability as an ideological construct is embedded within the collective consciousness of both powerful (non-disabled) and less powerful (disabled) groups through the workings of popular culture. Popular culture is an arena of struggle and negotiation between the interests of dominant and subordinate groups (Storey, 2005). While popular cultural forms are objective influences with potential power to shape what individuals may think and do, it is ultimately the subjective powers of individuals that determine what they *actually* think and do (Archer, 2003). Within a media-soaked society it is the role of the

unceasing flow of representations, amusements, celebrities, pseudo-events and spectacles on offer to ensure that public discourse is trivialised to the extent that meaningful criticism of existing social relations becomes difficult or unlikely. When news is packaged as entertainment, information is provided that gives the illusion of knowing but that actually prevents knowledge (Postman, 2006). What is known is banal. In a television age viewers' minds are conditioned by useless expectations and their critical faculties inhibited (Sigman, 2007). The point is not that ideology forces itself but that it sells itself. It seduces rather than imposes. Mass media audiences are not deceived into false consciousness but, rather, willingly participate and connive at their own oppression (Taylor and Harris, 2008:132).

The ideology of normality is substantiated through the constant circulation within popular culture of images and narratives representing impairment and disability as personal tragedy. Disability representations involve the endless repetition of a small number of stereotypes: the poor, pathetic victim, dependent on others for pity and charity; the bitter and twisted monster with a chip on his shoulder; the plucky, tragic but brave struggler, determined against the odds to triumph over adversity; the laughable incompetent, incapable of participating fully in everyday life (Rieser and Mason, 1992:96). The personal tragedy model is the cultural expression of the medical model and is materialised through the recycling of disciplinary messages that normality is good, abnormality is bad; that 'able-bodiedness' is valued, impairment and disability are the shameful marks of inferiority (Cameron, 2008:17). Tanya Titchkosky states that texts are always oriented social action, producing meanings: they act on us and help constitute our social contexts (Titchkosky, 2007:23). Popular cultural disability stereotypes play an important role in limiting the narratives available to disabled people to reflect on in constructing identity. Stephen Duncombe (2007:18) states that 'reality is always refracted through the imagination, and it is through our imagination that we live our lives'. Identity is not a fixed, inner characteristic but a struggle, emerging and re-emerging as the stories we use to live develop, and dependent upon the choices we make. It is a 'creative work of the imagination... grounded in the real world in which it functions' (MacAdams, 1993:112).

If the experience of disabled people of the real world is that it constantly 'tells us we're shit because we're disabled' (Fraser, 2004) then the imagination is given little on which to build that is positive. The personal tragedy model provides a storyline through which impairment can only be experienced as a discreditable personal characteristic.

What problematises grasping the idea of disability as oppression is the mundane, everyday level at which this takes place. As Iris Young observes, oppression involves:

the disadvantage and injustice some people suffer not because a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society (Young, 1990:41).

It is not that non-disabled people are conscious of their roles as oppressors or actively intend to oppress. The reverse might be said to be usually true: that non-disabled people generally feel sympathy towards people with impairments and seek their welfare. But it is precisely in this relationship, in which pity is experienced as an appropriate emotion, that oppression takes place so that disabled people experience injustice:

as a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions, media stereotypes, and structural features of bureaucratic hierarchies and market mechanisms –in short, the normal processes of everyday life (Young, 1990:41).

It is difficult to identify disability as oppression because this oppression happens within the fleeting, insignificant everyday. Fran Martin suggests that the difficulty in seizing hold of and recognising what goes on in the everyday arises:

partly because we are not trained to think of the repetitive activities and apparently banal objects that make up our everyday experience in an intellectual way. Instead, we tend to experience them as a kind of ubiquitous but unremarkable ‘background’ to the things in our life that we think ‘really’ matter (Martin, 2003:1).

The contexts and relationships through which lives and identities are constructed are allowed to pass without critical reflection: these are regarded as something individuals cannot really do very much about because they are just the way things are.

Self and identity

The position I take here is that, rather than being a part of an individual’s fixed and unchanging essence, the self is a phenomenological entity characterised by the ability to reflect upon itself in relation to others. As Sheldon Stryker expresses it, ‘one’s self is the way one describes to himself his relationship to others in a social process’ (Stryker, 2002:59).

If the self is an ongoing project, a perpetual fashioning or state of becoming, it can be said that the individual has many different selves or personalities, as many as there are identified separate social groups which respond to the person (Schmitt, 2003:98). For example, somebody may identify herself as a woman, a convert Muslim from a white Brethren family,

a daughter, a Scot, a West Coaster, a professional, a young person, a divorcee, before she identifies herself as a disabled person (I am describing Roshni, one of the participants in my research). As a disabled person she may well decide to identify herself as blind in distinction not only to people who have partial sight, but in distinction to deaf people, wheelchair users, people with mental health issues, people labelled as having learning difficulties, and so on. As Stryker remarks, the self needs to be recognised as a construct that is complex and differentiated, albeit organised, rather than as an undifferentiated unity. Identities, he adds, are ‘parts’ of self, internalised positional designations, existing insofar as a person is a participant in structured role relationships:

One has an identity when one is placed as a social object by others in the same terms that one appropriates and announces for oneself. One may have a long list of identities, limited only by the number of structured relationships one is involved in... which taken together comprise the self (Stryker, 2002:60).

Identity salience is the process through which a person decides what type of person it is important he is seen as. He will order discrete identities into a salience hierarchy

such that the higher the identity in that hierarchy, the more likely that the identity will be invoked in a given situation or in many situations (Stryker, 2002:61).

It is possible, then, or even likely, that when one identity among several is regarded as signifying inferiority, it will become an identity given less emphasis in a person’s self-conception or projection, or even avoided completely. Thus, for many people with impairments it can be said that they have no disability identity.

A further concept we can make use of in understanding the self is that of commitment:

To the degree that one’s relationships to specified sets of other persons depend on being a particular kind of person, one is committed to being that kind of person... Since entering into social relationships is premised on the attribution and acceptance of positions and associated roles, then commitments are premised on identities (Stryker, 2002:62).

If it is regarded as being of more value to be identified by others as a woman, a mother, a wife, a lover, an artist, than to be regarded as a wheelchair user, one is said to be committed to those identities and to reject disability identity. When disability is understood in terms of limitations arising as a result of impairment, it is not unusual for somebody to place more emphasis on the things she *can do* as a basis for self-understanding.

Self-Preoccupation and Consumerism

In addressing ‘the ideology of consumerism’, Conrad Lodziak criticises views which regard the self as inextricably bound up with choices made in the social sphere of consumption. It is maintained by advocates of consumer culture, Lodziak contends, that growing preoccupation with self-identity arises from changes accompanying late-modern shifts in patterns of social organisation (Lodziak, 2002:51).

According to Lodziak, consumerist mythology has it that individuals can no longer rely upon the relatively secure and stable foundations upon which identities were formed in earlier generations, or upon the security of knowing who they are in terms of being rooted in a secure job, a stable community spanning several generations and a relatively stable family. Whereas identities in the past were largely ascribed and worn on the basis of an individual’s place in terms of fairly inflexible power structures, recent social changes have created the need for new self identities and for new means for identity construction. New opportunities arise which enable individuals to choose their own identities in social contexts no longer constrained by tradition. It is down to the individual to decide who she is.

Lodziak comments with irony that:

oddly enough, for the ideology of consumerism, these new opportunities tend to be confined to those offered by consumer culture! In other words, consumer culture provides the resources that enable us to choose and express our self-identities (Lodziak, 2002:51).

Lodziak argues that the type of freedom (freedom from old constraints, freedom to choose who we are, freedom to buy our identity) propounded by the ideology of consumerism serves to conceal the social inequalities and areas of life in which freedoms are being increasingly limited and restricted in contemporary society. While options for identity- and lifestyle-choice are far more restricted for people excluded from financial resources, these people are not excluded from the barrage of images and texts which hold out tantalising possibilities.

When self-emphasis is required, identification in group terms – particularly in terms of identification with a devalued social group – will seem unattractive. To achieve distinction for getting it right - in terms of what to wear, what to listen to, which technological gadgetry to carry around - is seen as what matters. The possibility of regarding disability as a positive source of identity becomes unlikely. While engagement in struggles over image and style is regarded as being what is *really* important in life, participation in political struggle over

matters of social significance becomes unlikely. The ideology of consumerism closes down possibilities for such a course even to occur as a thought. Freedom is offered as the practice of making inconsequential choices that are ultimately insignificant either socially or to the self.

Individualisation

Norbert Elias has outlined ways in which, over several centuries, the body consciousness which came to characterise modernity, developing into the general requirements of respectability and hygiene, focused increasingly on continuous self-monitoring and the exercise of bodily self-control in every respect. Discussing Elias' position, Harvie Ferguson comments that:

appropriate dress, appearance, polite modes of eating and drinking, acceptable means of coughing, sneezing, urination and defecation, the proper restraint in gesture and forms of interaction, and the provision and protection of personal space all featured in the new corporeal pedagogy (Ferguson, 2006:106).

A constant and highly differentiated regulation of one's own behaviour is identified as evolving as societies become increasingly larger and more complicated. A social apparatus is established, Elias suggests, in which:

the constraints between people are lastingly transformed into self-constraints. These self-constraints, a function of the perpetual hindsight and foresight instilled in the individual from childhood in accordance with integration in extensive chains of action, have partly the forms of self-conscious control and partly that of automatic habit (Elias, 2000:375).

The individual experiences himself as an individual within modernity because it is in the continuously emerging interests of modernity, and in the interests of powerful groups shaping modernity, that he should do so. Through a social moulding process involving considerable formal education a person acquires the attributes, characteristic and modes of behaviour that distinguish him from every other individual within his society. It is society which produces the individual. As Elias puts it:

the individual can only be understood in terms of his communal life with others. The structure and configuration of an individual's behaviour control depend on the structure of the relations between individuals... The individual is only able to say *I* if and because he is at the same time able to say *we* (Elias, 2001:61).

In other words, everything the individual is and thinks and does is tied within an inescapable relationship to what goes on around her, to her past and present relationships with other people, and beyond them to the interlocking networks of relationships of which these others, in turn, are part. More than this, although most people do not know each other and will have hardly anything to do with each other, for all their freedom of movement they are tied to each other. There is a hidden order, not directly perceptible to the senses, which locates everyone in their particular place.

Elias has argued that the increased need for self-governance corresponds with the increased size of societies and the greater number of networks that is typically experienced by individuals. Standardised modes of thinking and behaving become the only acceptable practice when large numbers congregate and interact. In this lies the contradiction that the more uniquely one is made to sense his own individuality, the more he conforms with what is required of him and becomes like all the other individuals around him.

There is today a widespread modelling of the self-image which induces the individual to feel and think as follows: "I am here, entirely on my own; all the others are there, outside me; and each of them goes his way, just like me, with an inner self which is his true self, his pure *I*, and an outer costume, his relations to other people" (Elias, 2001:27).

While this way of thinking about the self and others may appear entirely natural and obvious, Elias' view is that it is neither:

It is an expression of a particular historical moulding of the individual by the network of relations, by a form of communal life with a very specific structure. What speaks through is the self-consciousness of people who have been compelled to adopt a very high degree of restraint, affect, control, renunciation and transformation of instinct, and who are accustomed to relegating a large number of functions, instinct-expressions and wishes to private enclaves of secrecy withdrawn from the gaze of the 'outside world', or even to the cellar of their own psyche (Elias, 2001:28).

Elias avoids the charge of over-determination by recognising that people differ in their natural constitutions. Individual constitutions (or the distinctness that each individual brings into the world and the way she perceives that distinctness) are, however, pliable.

Which individuality a human being finally evolves depends not only on his or her natural constitution but on the whole process of individualisation. Undoubtedly, the person's distinctive constitution has an ineradicable influence on his or her entire fate... Its fate, however it may turn out in detail, is as a whole, society specific (Elias, 2001:23).

Elias suggests that while the finer details may vary, the horizons open to the individual are fairly narrowly delineated within certain structures. The individual is offered a limited range of possible functions and available behaviours within which to shape his mode of being and his past is always there, shaping his present. While he has freedom to act and choose and think, this is only insofar as he is allowed by the structures of which he is part or by the web of relationships which have become absorbed as part of his personal character. All the functions of the individual are functions which he has for other individuals.

Each of these functions relates to others: it is dependent on their functions as they are dependent on it. By virtue of this ineradicable dependence of functions the actions of so many separate individuals... must incessantly link together to form long chains of actions if the actions of each individual are to fulfil their own purposes. And in this way each individual person is really tied; he is tied by living in permanent functional dependence on other people: he is a link in the chains binding other people (Elias, 2001:16).

Social change is an ongoing process which can never be entirely foreseen and which is neither the outcome of accident nor rational planning, but the outcome of a paradoxical constant system of pressures exerted by living people on living people.

While the observer overflying long stretches of history may notice first how little power people have over the main line of historical movement and change, the person acting within the flow may have a better chance of seeing how much can depend on individual people in individual situations, despite the fixed general direction. Only both observations together – far from contradicting each other – yield, if properly linked, a more revealing, more adequate picture (Elias, 2001:48).

Society is, in Elias' terms, both very firm and very elastic (Elias, 2001:48). Everyday life presents individuals with choices, which can be either taken, avoided or lost. Decisions are there to be made and by these decisions futures are shaped. The destiny of large numbers of individuals may depend on the decisions of other individuals, and on the social positions of these other individuals, to whom they are linked, from families to social groups to nations.

Upon these choices may depend whether tensions present in current situations are resolved here and now, or at some point in the future, or never at all. It is not, however, the individual who determines when these choices shall appear.

They are prescribed and limited by the specific structure of his society and the nature of the functions people exercise within it. And whatever opportunity he seizes, his deed becomes interwoven with those of others; it unleashes further chains of actions, the direction and provisional outcome of which depend not on him but on the distribution of power and the structure of tensions within this mobile human network (Elias, 2001:49).

This discussion of Elias' thought can be related to my thesis in a number of ways.

Firstly, the systematic exclusion of people with impairments from the social mainstream can be related to the privatisation of what have become perceived as shameful, embarrassing or fearful aspects of life and their removal from public view. It is

socially instilled fear in the form of shame and embarrassment, for example, which causes the individual to feel that 'inside' himself he exists as something that is quite alone, without relations to other people (Elias, 2001:27).

Elias' argument is similar to Barnes' cited above, that the removal of people with impairments from the social mainstream needs to be considered in the context of developing disciplinary practices. People with impairments are excluded from the social stage to make more easily forgettable those parts of life that society comes increasingly to regard as objectionable.

Secondly, normalising processes and expectations of conformity, together with the elevation of individual identity above group or social identity, make it unlikely that people with impairments will regard impairment and 'impairment effects' as positive characteristics upon which to build identity (Thomas, 1999:156). Positive identification as disabled will be unusual and will depend on being presented with choices that are heavily contingent.

Closely linked to this is the dehumanisation of people with impairments who have been identified, until comparatively recently, in terms of a homogenous mass as 'the handicapped', 'the disabled', 'the blind', 'the deaf', 'the lame', 'the mad'. With this oppressive situation as the backdrop the assertion of individuality becomes seen as being of primary importance. Positive change is recognised as involving the increasing validation of individuality.

In Elias' view it is only when the individual stops regarding himself as the starting point of his thought and comes to see himself as part of a much wider human network that his sense of alienation from others will gradually fade.

The Ascription of Inferiority

Writing with John Scotson, Elias (1994) has argued that the ascription of inferiority by powerful social groups towards less powerful social groups is a part of the operation of power relationships within societies characterised by conflict. Elias and Scotson maintain that two functions are achieved by this. The first of these is to do with the enhancement of the esteem with which members of powerful groups regard themselves. The second involves an internalisation of the typification as inferior and a rejection of self by members of less powerful groups. The social slur cast through cultural representations within dominant discourse of less powerful groups as inferior human beings is seen as entering the self-image of members of less powerful groups, weakening and disarming them as social groups.

A person's we-image and we-ideal form as much part of a person's self-image and self-ideal as the image or ideal of him- or herself as the unique person to which he or she refers as "I"... a person's group identity form(s) as integral a part of his personal identity as others which distinguish him from other members of his we-group (Elias and Scotson, 1994:xlirii).

When a person's 'we-image' or group identity is identified by that person as carrying an unhelpful stigma it is perhaps unsurprising that, as an individual, she should seek to disassociate herself from the group and go to lengths to avoid contact with other members of that group. Attempting to be identified with the powerful group is considered a rational response.

The first point above is reinforced by Rosemarie Thomson's description of the *normate* as:

the constructed identity of those who, by way of bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them (Thomson, 1997:8).

Thomson suggests that the term *normate* describes the subject position of those whose sense of identity as definitive human beings is given shape by the positioning of *others* identified in terms of abnormality and deviance. As John Swain and I have argued, the social identities of those who consider themselves normal (or able-bodied) are secured through processes involving the marginalisation of others (disabled people) who are identified in terms of their

departure from an imagined ideal (Swain and Cameron, 1999:75). By representing disability as misfortune and disabled people as unfortunate, the non-disabled can shore up their own perceptions of themselves as desirable and attractive.

Quoting the historian Paul Longmore, Mary Johnson speaks of the implicit bargain that is struck between society and people with impairments:

We will extend to you provisional and partial toleration of your public presence – as long as you display a continuous, cheerful striving towards ‘normalization’ (Johnson, 2003:118).

Disabled people are required to internalise the values which tell them that they are inferior and to smile bravely. The performance of this role gives legitimacy to structural relationships of inequality. Drawing upon Judith Butler’s arguments on gender, disability is not a property or attribute of subjects or their bodies but a shifting effect of ideological practices. Disability is not so much something people with impairments *have* as something they *do*. It is something produced performatively, constructed through multiple acts of disabling practice, and is a:

repeated stylisation of the body , a set of repeated acts within a highly regulatory frame that congeal over time to produce the appearance of a substance, of a natural sort of being (Butler, 1990:33).

In that the constructed identities of disabled people are understood and recognised by both disabled and non-disabled people as inferior, the superiority of non-disabled embodiment is established.

The second point above, involving the rejection of identification of self with group identity, has been documented widely in the context of disability and is reflected in the following statements by disabled people:

If I saw anyone who was disabled I didn’t want to talk to them, and if I did talk to them it was as if I was able-bodied talking to them, doing the old patronising bit (Shakespeare et al., 1996:51)

Growing up, I wanted to dis-identify myself with the image or label of being a cripple. As I grew older, I sought out attractive lovers as a way of establishing my own normalcy. I avoided other disabled people. I refused to see myself as part of that group (Tollifson, 1997:106).

[I'm] a normal person. The only difference is I'm in a wheelchair, and I try not to think of that as a difference (Watson, 2002:514).

A reluctance to consider oneself or to be considered by others as disabled, to hide or to deny the significance that impairment has in one's life, is a frequent way of dealing with the attribution of inferiority associated with impairment. The strategy of passing, for disabled people able to hide their impairments, can be adopted as an attempt to avoid discrimination or ostracism. In Simi Linton's words, passing

may be a deliberate act to protect oneself from the loathing of society or may be an unchecked impulse spurred on by internalised self-loathing (Linton, 1998:20).

Imposed and intrinsic relevances

At the heart of this matter lies a question: is there anything to be gained by identifying as disabled? So far I have given reasons why such an identity is often avoided, as well as reasons suggesting such an identity could only be regarded negatively.

Answering this question involves addressing the conflicting meanings that people have in mind and the conflicting models they hold when they use the term disability. Anselm Strauss notes that:

the point is not whether or not (an individual) can be wholly indifferent to his name but that an extensive range of reaction can be evoked by his imaginings of what he must look like to certain audiences if he bears the name that he does (2008:18).

Outlining what he means by the term interpellation, Louis Althusser likens this process to being hailed "*You there!*" in the street by a policeman:

The hailed individual will turn round. By this mere 180 degree physical conversion, he becomes a subject. Why? Because he has recognised that the hail was 'really' addressed to him (Althusser, 2008:48).

It is through ideology that individuals acquire and articulate their sense of selves as social beings: who they are, what they represent and how they act. Ideology interpellates individuals into particular forms of subjectivity which they assume or internalise as 'natural'. Through countless everyday practices interpellation involves the naming of individuals so that they are consistently and subtly recruited as subjects. Being interpellated as disabled constructs the impaired subject as the disabled subject and bears distinct kinds of

expectations around roles and horizons. When somebody who is impaired hears the word 'disabled' she recognises herself and the subject she is expected to be. Even when the term is rejected it is a name that she knows has been applied to her as a description betokening inferiority.

Alfred Schutz uses the term *imposed relevances* to describe

situations and events which are not connected with interests chosen by us, which do not originate in acts of our discretion, and which we have to take just as they are (Schutz, 1970:114).

Imposed relevances such as barriers preventing equal participation within community life, inadequate and badly designed housing, lack of access to public transport, substandard education, few employment opportunities, lack of information, lack of control over personal decision-making processes, inaccessible leisure facilities, experiences of oppressive care and unwelcome intrusion, of being objectified as objects of pity, compassion, curiosity or hatred, being made the subject of stereotyping judgements and condescending assumptions, are part and parcel of the experience of being disabled. This is the case for people with impairments whether they accept or reject disability as a foundation for constructing identity.

Schutz suggests that

we have no power to modify them by our spontaneous activities except by transforming the relevances thus imposed into intrinsic relevances (Schutz, 1970:114).

Intrinsic relevances he describes as

the outcome of our chosen interests, established by our spontaneous decision to solve a problem by our own thinking, to attain a goal by our own action, to bring forth a projected state of affairs (Schutz, 1970:114).

I contend that there is much to be gained by identifying as disabled if this involves transforming imposed relevances into intrinsic relevances in order that these can be addressed. Involved here is a process Friere has described in terms of agents singling out elements from their 'background awareness' and reflecting upon these, making them objects of consideration and objects of action and cognition (Friere, 1974:56). This requires an altered subjectivity and a naming of disability as oppression, and is part of a process that Simi Linton has called 'claiming disability' (Linton, 1998). It requires a conscious

acknowledgement of the processes by which people with impairments are interpellated as disabled and a conscious decision to adopt a subversive stance towards these.

Disability Politics

For so long as disability is rejected as a foundation on which to build identity people with impairments are unable to resist oppression. Oppression is unrecognised as such but is rather treated as a natural part of experience, being the ordinary outcome of physical impairment. Imposed relevances remain ‘unclarified and incomprehensible’ (Schutz, 1970:114). Each disabled person continues to internalise ideological conventions and requirements and then unconsciously uses these as the standards against which to measure and modify both identity and physicality (Cameron, 2008).

It is not considered part of the role of disabled people to criticise society from a minority perspective. Disabled people are not regarded as a minority with its own distinctive way of life and traditions like women or ethnic groups, who it is acknowledged perhaps do have reasonable grounds for viewing society from a different perspective, but are viewed by the non-disabled majority as being:

just like us – but less: ‘disabled’... unable; defective... ‘failed normals’... merely that.
A disabled person (is) nobody but our uncle who had the bad luck to be injured on the assembly line, our sister (with) multiple sclerosis (Johnson, 2003:124).

Pressures to discourage people with impairments from identifying collectively are embedded within everyday life practices. Those who complain about injustice are labelled as *complainers... who cannot deal with the problems related to their disabilities* (Murphy, 2005:161) and are identified and treated as bitter people who have just not come to terms with their limitations.

Nevertheless, the past four decades have witnessed the emergence of a new social movement of disabled people who have organised around the social model and campaigned across a diverse range of areas: through the establishment of centres for inclusive living and for the right to direct payments to meet support needs; for anti-discriminatory legislation; through the establishment of coalitions which have raised consciousness around the planning and delivery of public services; through the development of representative national and international lobbying bodies; through the growth of Disability Arts as a cultural practice reflecting the experience of living with impairment in a disabling society; through the

establishment of Disability Studies as an academic discipline addressing issues concerning not just the meaning of disability but the nature of society.

In Jane Campbell and Mike Oliver's words, the growth of this movement

was not merely a numerical phenomenon, but also reflected the individual and collective empowerment of disabled people through the organisations they were creating. This can be seen ... in the challenge to dominant social perceptions of disability as personal tragedy and the affirmation of positive images of disability through the development of a politics of personal identity (Campbell and Oliver, 1996:20).

Carol Thomas has noted that this politics of identity is fundamentally bound up with having an impaired body (where impairment is recognised as a fixed physical characteristic) as well as being disabled (seen as socially constructed difference) (Thomas, 1999:113). These differences are affirmed and celebrated rather than hidden or regarded as sources of inadequacy. They become the focus for engagement with the world. Allan Sutherland sums this up:

We break through the idea, presented to us by the medical profession and disability charities in particular, that our situations are different and unrelated, and come together not as the blind or the deaf or the epileptic, or the spastic or the arthritic, but as disabled people (Sutherland, 2004:unpaged).

Disabled people come together as people with different impairments who recognise a commonality of oppression. John Fiske has noted that:

The recognition of social difference produces the need to think differently: thinking differently reproduces and confirms the sense of social difference. What is crucial here is that the thinking is different: not divorced from social reality: thinking differently involves the subordinate in making their sense of their subordination, not in accepting the dominant sense of it or in making a sense with no relationship to domination (Fiske, 1995:58).

While the focus of campaigning activity in the disabled people's movement has concentrated largely on addressing physical and social barriers preventing access to opportunities and life chances, this is not to say that impairment has been downplayed. The 'thinking differently' within the movement has involved a rejection of the idea that impairment is inherently tragic and a claim for the rights of people with impairments to be recognised as different but equal.

This involves a demand for recognition that to do things differently – in a way that diverges from the culturally expected way - is not to do them in an inferior way but in a way that meets individual requirements. The thinking differently of the disabled people's movement involves a fundamental rejection of assumptions regarding aspects of physicality, behaviour and the shamefulness of non-conformity identified by Elias above.

Speaking about valuing what *actually is* instead of being caught up in and entranced by *what we think could be better*, Joan Tollifson states that

Imperfection is the essence of being organic and alive. Organic life is vulnerable; it inevitably ends up in disintegration. This is part of its beauty (Tollifson, 1997:106).

To identify positively as impaired and disabled involves a redefinition of the relationship between *us* and *them*. Whereas in the past *they* (non-disabled people) were identified as superior to *us* (disabled people) the ideological origins of such a perception are questioned. The high value placed on normality and conformity is identified as serving the interests of governance rather than the needs of human beings.

This does not, however, involve a denial of the physical pain or fatigue that impairment may cause, or that impairment effects create limitations which mean that ordinary ways of doing things are not possible. Instead of regarding these facts as invalidating the worth and experience of people with impairments, it validates and affirms these as a legitimate part of diverse human experience.

To say *I am disabled* is not to say *I have an impairment* but is to make a statement about the situation of people with impairments in a disabling society. Furthermore, to say *I am disabled* collectively with other disabled people as an expression of anger turns this into a statement of pride:

By modifying the frame from one of innate deviance to one of oppression, individuals may come to feel angry not only because the system is unjust but because they have been made to feel ashamed... The activated feeling of anger propels stigmatized individuals into public space to behave collectively, and feelings of pride emerge (Britt and Heise, 2000:257).

Transforming imposed relevances into intrinsic relevances in this context involves a realistic appraisal of one's material situation. It involves bringing the surroundings within which one experiences life to the forefront of consciousness and critically holding them up for interrogation.

This is, however, not always an easy process for, as Henri Lefebvre observes:

in good faith, the individual – be he bourgeois or proletarian – can deny his experience of social classes since objective social reality functions beyond his own ‘subjectivity’, beyond his own private consciousness (Lefebvre, 2008:165).

It is the easiest thing in the world for the impaired individual to deny his experience of disability as a social relationship for the same reason. Paulo Friere comments that

As long as the oppressed remain unaware of the causes of their condition, they fatalistically ‘accept’ their exploitation. Further, they are apt to react in a passive and alienated manner when confronted with the necessity to struggle for their freedom and self-affirmation (Friere, 1974:40).

Simon Stevens distinguishes between ‘real’ disabled people and politically active disabled people involved in ‘the movement’:

I would argue from experience that many disabled people do not understand the social model or become involved in the politics of disability because they are too busy getting on with their lives (Stevens, 2008:10).

It is, however, at the everyday level – at which people busily get on with their lives – that oppression is experienced. The misrecognition of oppression does not mean that oppression does not exist. Iris Young argues that:

The conscious actions of many individuals daily contribute to maintaining and reproducing oppression, but these people are usually simply doing their jobs or living their lives and do not understand themselves as agents of oppression (Young, 1990:42).

In its nature as structural oppression disability operates subtly through everyday practices and is therefore difficult to recognise. The cultural imperialism of the non-disabled permeates disabled people’s lived experience so thoroughly that the possibility of its contestation either goes unnoticed or is explicitly denied. While the disabled people’s movement has been an important force in the lives of many – transforming lives of self-loathing into lives of assertive defiance – there are many more whose lives remain characterised by the experience of oppression and dependence.

Habitus

A useful insight can be drawn by reflecting upon Pierre Bourdieu's concept of the habitus. Identifying habitus as arising from conditionings associated with a particular class of conditions of existence, Bourdieu explains what he means by the term:

systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which organise and generate practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends (Bourdieu, 1990:53).

Habitus is absorbed by individuals as a set of ways of thinking, feeling, knowing and doing within the social environment from which they emerge and of which they are part. It involves a learned recognition of one's place and the limits of practical possibilities. Habitus is inculcated through everyday patterns of social practice, through roles allotted and taken on, through expectations held and through common sense assumptions about what is right and normal. It is a useful explanatory concept to account for the reasons why people think and behave and talk in certain ways that, while being the outcome and expression of free will and individual intention, simultaneously reinforce existing oppressive patterns of social organisation.

In another description, Bourdieu characterises the habitus as:

embodied history, internalised as a second nature and forgotten as history... the active presence of the whole past of which it is the product (Bourdieu, 1990:56).

While Bourdieu's discussion of the habitus is most usually related to social class, I suggest that the idea of a *disabled habitus* provides a useful explanatory tool for making sense of themes arising within this thesis. To talk of a disabled habitus is to talk of a learned way of being in the world.

Drawing upon Bourdieu, Simon Charlesworth states that:

Our understanding must... contain a sense of destiny and fate, because being born into particular class locations at a particular historical moment involves individuals in being cast into a temporal frame and trajectory, that manifests the effects on individuals of over-arching social and class processes that affect the life-course in all its details of living and being (Charlesworth, 2000:94).

While class relationships are inextricably bound up with disability relationships, it is possible here to gain illumination by simply substituting the word *class* in Charlesworth's statement with the word *disability*. Disability habitus, viewed here as an absorption of dominant ways of thinking about disability, involves an acceptance (which can be either passive or reluctant) of the view that this is just the way things are. Using an analogy of participation in a social field as game playing, Bourdieu notes:

Because native membership in a field implies a feel for the game in the sense of a capacity for practical anticipation of the 'upcoming' future contained in the present, everything that takes place in it seems sensible, full of sense and objectively directed in a judicious direction (Bourdieu, 1990:66).

While aspects of experience may be sensed by the disabled individual as unfair and unjust, possession of the disabled habitus confirms that at least they make sense. Impairment is identified as the cause of misfortune. This raises the question of whether people with congenital impairments or impairments gained at an early age better are thereby 'better' equipped for survival as disabled people than those who acquire impairments in adulthood. Certainly Bourdieu suggests that

the earlier a player enters the game and the less he is aware of the associated learning... the greater is his ignorance of all that is tacitly granted through his investment in the field and his interest in its very existence and perpetuation and in everything that is played for in it, and his unawareness of the unthought presuppositions that the game produces and endlessly reproduces, thereby reproducing the conditions of its own perpetuation (Bourdieu, 1990:67).

This can be seen, for example, in the support given by many disabled people to large charities *for* disabled people which place an emphasis on cure and rehabilitation as opposed to organisations run *by* disabled people which have a rights agenda. It can be seen in the identification of many disabled people with the interests of 'carers'. While a critical disability perspective identifies care as a problematic concept, part of the network of structural relationships which maintain disability oppression (Swain and French, 1998), this is usually perceived as a benign concept and role when regarded in everyday terms.

Among the reasons why the majority of disabled people do not engage with disability politics is the reason that this flies in the face of common sense as experienced at the everyday level. Susan Willis has pointed out that one of the problems with the separatist approach to social injustice is its tendency to be seen as 'so different from dominant culture

as to have no impact on the rest of society' (Willis, 1991:34). To many disabled people, disability politics seems either an irrelevance or the activity of extremists who have not adjusted themselves to the way the world is.

Redistribution or Recognition?

In opening a political-philosophical debate with Axel Honneth on strategies for the pursuit of social justice, Nancy Fraser has stated that:

Claims for social justice seem increasingly to divide into two types. First, and most familiar, are redistributive claims, which seek a more just distribution of resources and wealth... Today, however, we also encounter a second type of social justice claim in the 'politics of recognition'. Here the goal... is a difference friendly world, where assimilation to majority or dominant cultural norms is no longer the price of equal respect (Fraser and Honneth, 2003:7).

In that its focus has been on addressing barriers to participation in ordinary life, disability politics has had an agenda that can, in Fraser's terms, be described as redistributionist. As a tool to be used in identifying and removing barriers the social model is a redistributionist model. The activity of the disabled people's movement has also, however, been characterised by a politics of recognition.

The recognition paradigm... targets injustices it understands as cultural, which it presumes to be rooted in social patterns of representation, interpretation, and communication (Fraser and Honneth, 2003:13).

Within the Disability Arts Movement, a distinctive disability culture rooted in the life experiences and perceptions of disabled people, narratives have been developed which challenge dominant portrayals of disability. Slogans such as *Disability Pride* and *Piss on Pity*, emblazoned on t-shirts worn at cabarets, street demonstrations and in the course of ordinary life, have made visible a strength and connection which makes little sense to an onlooking world. As with other marginalised and disempowered social groups the identity politics of the disabled people's movement has invested heavily in claims to recognition on its own terms as a social group. However, as Benjamin Ardit and Jeremy Valentine have observed, there is a danger inherent in such a stance:

...the affirmation of particularity can, and often does, have the perverse effect of deriving the dignity of the subject from its determined or constrained nature... In so far as such situations are produced through inequality, then this inequality becomes

internalised as the positive expression of the dignity of the subject... (Arditi and Valentine, 1999:73).

While, then, there is much to be gained by identifying as disabled, I would suggest that there is a need to regard disability identity as a strategic garb to be worn on a road towards the full inclusion of people with impairments as equals within ordinary community life. Taking on a disabled identity involves 'turning back upon the stream of consciousness in which we are immersed in everyday life' (Schutz, 1997:47). But it is an identity to be regarded as describing not so much the impaired self as the social positioning of the impaired self. There is an important difference between being positive about disabled people and being 'positive about disability' (Barking-Dagenham.gov.uk 2010: unpagged).

Acknowledgement

In considering ways in which the reification of disability may be avoided in the processes of disability politics, so that the distinction between impairment and disability remains visible, I want to draw on a conception of justice developed by Patchen Markell. Markell is critical of ideas identifying social justice as rooted in the recognition of others' identities, and argues that a firmer basis involves the acknowledgement by individuals of the finitude of self in the face of unpredictability and uncertainty.

This is an approach which suggests a need for individuals to become critically aware of the thoroughly social nature of the self and to reject the kinds of selves that long training has produced. Addressing the ideal of recognition, Markell suggests this is anchored in:

the prospect of arriving at a clear understanding of who you are and of the nature of the larger groups and communities to whom you belong, and of securing the respectful recognition of these facts by others (Markell, 2003:12).

The supposition, he suggests, is that

mutual recognition of this sort would eliminate the obstacles of misunderstanding, ignorance, and prejudice that alienate us from each other and ourselves, making it possible for us to act in accordance with who we really are, and to do so with the support rather than the resistance of our fellows (Markell, 2003:12).

We can see that in establishing the right to be valued as disabled people, disabled people engaging in disability politics have made a claim to recognition as a social group that is systematically disadvantaged. The ideal outcome of recognition of this claim would be

general public acceptance of the position that disability is an unequal social relationship and a concerted effort to remove disabling barriers.

This approach is limited, Markell contends, in that it offers too simplistic an understanding of how real life really happens. While he contrasts recognition approaches favourably with individualistic approaches to addressing social injustice, he suggests that the politics of recognition is limited by its very specific focus on the influence of individual background or past experience within the present as identity.

Individualistic approaches to the empowerment of disabled people can, for example, be characterised in attempts by disability industry professionals to increase individuals' everyday life choices through, for example, what is known as Person-Centred Planning. These approaches, however, do not take account of the historical injustices by which disabled people's experiences have been and continue to be structured. In other words, they do not recognise the existence of what I have termed the disabled habitus. To see the remedy to the disadvantage experienced by disabled people as lying simply in offering more choice within unchanged structural relationships is to ignore the wider picture.

It is an individualistic approach which is represented in the position of Stevens' disabled people 'too busy getting on with their lives' to understand the social model or to become involved in the politics of disability. The business of getting on with life does not take into account what Markell describes as 'the moral weight either of unchosen attachments and memberships... notwithstanding efforts to will them away' (Markell, 2003:12).

Measured against individualistic approaches to social justice, Markell identifies the politics of recognition as progressive in that it acknowledges the impact of background as structuring experience of the present by understanding this history as identity, where

identity is understood specifically as an antecedent set of facts about who we are, telling us what acting authentically means for us (Markell, 2003:12).

If it is our identities that determine our thoughts and words and actions then it is clear why it is important to have our identities recognised by other people. If we think and talk and behave in certain ways *because* we are disabled people, gay men, black women, or old age pensioners, then it is a crucial matter in terms of empowerment that our identities are validated and respected in these terms.

However, Markell contends, this is an unpersuasive picture of the relationship between identity and action. The weakness of recognition politics is that it can lead to situations in

which identity becomes regarded as a fixed characteristic. In Markell's terms identity is continuously produced through people's words and actions in everyday life, in other people's reactions to these, and in their multiple varieties of social interactions:

Because we do not act in isolation but interact with others, who we become through action is not up to us; instead, it is the outcome of many intersecting and unpredictable sequences of action and response (Markell, 2003:13).

Whereas our sense of who we are is in actuality an ongoing process, emerging in the course of the ongoing and uncertain interactions in which we engage in everyday life, by treating identity as static the politics of recognition does not allow room for acknowledgement of our *intersubjective vulnerability* (Markell, 2003:14).

The issue here has to do with forms of self-consciousness that have dominated western thought in modernity. As Elias (2000) and Foucault (1998) have shown elsewhere, consciousness of the autonomous self, separated and alienated from all others by its own embodiment, is enmeshed with processes aimed at establishing ever-increasing subjection, discipline and control (of nature, of self, of body). The weakness of the ideal of recognition, Markell suggests, is its entanglement within and validation of a particular historical construction of the self. Its problem is to do

with the way in which it expresses the aspiration to a sort of sovereign invulnerability to the open-endedness and contingency of the future we share with others (Markell, 2003:15).

The politics of recognition is inadequate as a diagnosis and response to 'the underlying relations of subordination that give rise to systematic, identity-based social and political inequality' (Markell, 2003:17) because its aim is caught up in the contradictions of autonomous individualism. While disabled people seek a resolution of injustice by gaining equality with non-disabled people (perceived as relatively autonomous agents) by gaining similar degrees of autonomy, injustice will not be addressed but merely reproduced in a slightly different form. It is the very idea of the autonomous individual which must be called into question if the oppressive social relationship of disability is to be removed. The answer lies not in the non-disabled changing their attitudes towards disabled people, but in addressing their own understanding of themselves.

Iris Young suggests that structural oppression refers to:

the vast and deep injustices that some groups suffer as a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions (Young, 1990:41).

The systemic oppression of some social groups by others occurs not as a result of conscious decisions to dominate and control but rather as a result of the self-interested attempts by the powerful to preserve themselves from exposure to threats to their own self-image, autonomy, prowess, longevity, welfare. Thus, non-disabled people are caught up in wider social processes related to capitalist interests which require that they should prize highly self-identification as distinct, autonomous individuals.

In Markell's view social subordination involves:

closing off some people's practical possibilities for the sake of other people's sense of mastery or invulnerability; and it is the exploitative character of this relationship, rather than some lack of correspondence between how people are regarded and how they really are, that makes it unjust (Markell, 2003:23).

Markell's point here echoes Tom Shakespeare's description of disabled people as 'dustbins for disavowal', onto whom are projected the anxieties of non-disabled people, perpetually anxious to deny their own mortality and physicality:

It is not just that disabled people are different, expensive, inconvenient, or odd; it is that they represent a threat... to the self-conception of western human beings – who, since the Enlightenment, have viewed themselves as perfectible, as all-knowing, as god-like: able, over and above all other beings, to conquer the limitations of their nature through the victories of their culture (Shakespeare, 1997:235).

There is a functional purpose to the marginalisation and cultural oppression of people with impairments within the modern capitalist enterprise. The constant generation of needs, consumption and profit involves a requirement of individuals to possess a specific type of self-conception which conceives of itself as self-sufficient and self-determining. Impairment poses a challenge to this view of the self and is therefore represented as abnormality and inferiority.

The structural arrangements which shape the experience of the powerful by isolating the less powerful do not, however, provide the sovereignty desired. This desire, Markell argues, is impossible to fulfil, because it has its roots within a misrecognition of the basic conditions of human activity. Nevertheless:

subordination insulates some people from the force of the contradiction between the desire for sovereignty and the ineliminable fact of finitude, enabling them to live within that contradiction at other people's expense... We might say that social structures pay an ontological wage: they organise the human world in ways that make it possible for certain people to enjoy an imperfect simulation of the invulnerability they desire, leaving others to bear a disproportionate share of the costs and burdens involved in social life (Markell, 2003:22).

Disability is the ontological price paid by people with impairments for the relative security and comfort of people able to occupy the normate position. The position of the normate is one that is valued and rewarded because it involves the fulfilment of the role that contemporary social organisation requires. However, it is also a position which is less than fulfilling of human potential and involves the ultimately futile pursuit of meaning within the alienating products of the capitalist system.

Markell argues that oppressive relations between social actors are not the result of misrecognition of others, but stem from contradictions in our ways of understanding the self. Acknowledgement avoids this trap, being

directed at the basic conditions of one's own existence and activity, including, crucially, the limits of 'identity' as a ground of action, limits which arise out of our constitutive vulnerability to the unpredictable reactions and responses of others (Markell, 2003:36).

He emphasises that acknowledgement is not a magical recipe for removing from human relations 'the full range of experiences that can make social life unpleasant or difficult to bear' (Markell, 2003:37) and identifies this kind of promise as a weakness inherent in prognoses offered by both supporters of redistribution and recognition politics. The view that all it will take to put things right for once and for all is a fairer distribution of resources or a recognition of 'who we really are' is naive and flies in the face of historical experience. Rather, in being directed towards our own conditions, acknowledgement

accepts our finitude, and involves coming to terms with, rather than vainly attempting to overcome, the risk of conflict, hostility, misunderstanding, and alienation that characterises life among others (Markell, 2003:38).

I regard Markell's position as important because it does not seek to theorise away the reality of pain, discomfort, darkness and fatigue that real life involves. Whereas the project of

modernity has involved many attempts to eliminate these facts from human society, they persist in remaining. Markell offers a way of establishing a requirement that impairment be acknowledged as a fundamental and ordinary characteristic of human experience.

The Affirmative Model of Disability

Criticism of the social model of disability is not new and has been a focus for writers in Disability Studies almost since Michael Oliver first used the term as a description of the UPIAS principles in 1983 (Barnes, 2004). For example, disabled feminists have stated that the social model over-emphasises socio-structural barriers and ignores personal and experiential aspects of disability. Jenny Morris (1991:10) has suggested that ‘there is a tendency within the social model to deny the experiences of our own bodies’; Liz Crow has argued for a renewed social model which would allow ‘a more complete recognition and understanding of individual’s experiences of their body’ (1996:210). Carol Thomas (1999:47) has developed a social-relational definition of disability to account for the ‘socially engendered undermining of the psycho-emotional well-being of disabled people’. Tom Shakespeare, drawing upon feminist theory, contends that the social model has provided disabled activists with a framework through which they ‘could deny that impairment was relevant to their problem’ (2006:33).

The response to these criticisms made by social modellers has been that ‘the social model is nothing more or less than a tool with which to focus on those forces, structural and social... that shape our understanding and responses to people with designated impairments’ (Barnes, 2007). The social model is not an all-encapsulating theory of disability (Oliver, 1996) but a framework through which disability can be recognised as social process. Without impairment there is no social model of disability. While disability is not the only collective social response that could be made to impairment (the major thrust of the disabled people’s movement has been to demonstrate this), without impairment as a departure from and challenge to valued norms of physical embodiment in bourgeois society, disability as a specific form of social oppression would not exist. The fact that much of the movement’s campaigning activity has focussed on structural and environmental barriers reflects (perhaps controversial) positioning decisions rather than a weakness of the social model.

One intervention within the structural/individual, barriers/experience debate was made by John Swain and Sally French in a *Disability and Society* article in 2000 entitled *Towards an Affirmation Model of Disability*. Here they proposed an affirmative model:

essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle of being impaired and disabled' (Swain and French, 2000:569).

Rooted within perspectives emerging from the disability arts movement, and aiming to build upon 'the liberatory imperative of the social model' (Swain and French, 2000:569), the affirmative model is identified as a critique of the dominant personal tragedy model corresponding to the social model as a critique of the medical model. In proposing an affirmative model Swain and French – drawing upon the writings and experiences of disabled people - set out a position from which it can be asserted that, far from being necessarily tragic, living with impairment can be experienced as valuable, exciting, interesting and satisfying. This is not to deny that there can be negative experiences resulting from impairment, but to note that this is not all that impairment is about.

The explanation given by Swain and French of the need for an affirmative model relates both to the feminist and social modelist perspectives described above. By disassociating impairment from disability, they argue, the social model leaves open the possibility:

that even in an ideal world of full civil rights and participative citizenship for disabled people, an impairment could be seen to be a personal tragedy' (Swain and French, 2000:571).

The rejection of a tragic view and establishment of an affirmative model is not a concern of the social model. The feminist position 'of admitting that there may be a negative side to impairment' (Swain and French, 2000:571) is also regarded as problematic. John Swain has observed that when challenges are made to the social model on the grounds that it ignores impairment, this is always from the perspective that impairment is something awful, characterised by pain and chronic illness (Cameron, 2008:19). In arguing for an extension of the social model in order to include the personal, feminists are not making a claim for the recognition of the rights of disabled people to enjoy being who they are.

The 2000 article has been developed and elaborated upon in Swain and French's 2008 book *Disability on Equal Terms*. Outlined here is a clear statement of what the affirmative model *is* and *is not* about.

The affirmative model *is* about:

- being different and thinking differently about being different, both individually and collectively

- the affirmation of unique ways of being situated in society
- disabled people challenging presumptions about themselves and their lives in terms of not only how they differ from what is average or normal, but also about the assertion, on their own terms, of human embodiment, lifestyles, quality of life and identity
- ways of being that embrace difference

The affirmative model is *not* about:

- all people with impairments celebrating difference
- disabled people ‘coming to terms’ with disability and impairment
- disabled people being ‘can do’ or ‘lovely’ people
- the benefits of living and being marginalised and oppressed in a disabling society

(Swain and French, 2008:185)

However, Swain and French are clear that what is being proposed offers ‘no clearly defined formulas for change’ and ‘no comfortable remit’:

the affirmative model itself does not provide a different set of presumptions to replace those that characterise individual models, particularly the tragedy model (Swain and French, 2008:186).

In a chapter entitled *Further Towards an Affirmation Model* in a 2008 Disability Press publication (written before the issue of *Disability On Equal Terms*), I argued that to avoid any ambiguity around the meaning of the affirmative model, a set of definitions are required. Referring to Swain and French’s original article I made the point that:

While we are told what the affirmative model is ‘about’ and what it is ‘like’, we are not told what it ‘is’ (Cameron, 2008:23).

My main concern had been that, because the precise meaning of the term had been left vague, the possibility was left open that the affirmative model could be understood as suggesting that there are benefits grounded in the experience of being disabled in terms of experiencing an unequal social relationship (Cameron, 2008:20). Further, I was concerned that a rejection of the personal tragedy model might be conceived simply in terms of reversing this picture to emerge with an equally demeaning set of assumptions. A day centre manager at a Disability Equality Training session I ran in Edinburgh a few years ago commented:

I'm glad you've told us about the affirmative model. We've been using the affirmative model for years. We think all our users are lovely people (Cameron, 2008:24).

In a discussion I had last year with Nick Watson of Glasgow University, he dismissed the affirmative model as 'the Pollyanna model of disability', as if it provides some sort of structure within which disabled people are encouraged to play 'the glad game' (Porter, 2003).

To this purpose, I tentatively proposed the following as affirmative model definitions:

Impairment: physical, sensory and intellectual difference to be expected and respected on its own terms in a diverse society.

Disability: the loss or limitation of opportunities to take part in community life on an equal level with others due to physical and social barriers

(Cameron, 2008:24).

My primary concern was to ensure that the experience of impairment within an affirmative model remained identified as linked to the experience of disability as social oppression. The definition of disability I proposed was a variation of the Disabled People's International's social model definition adopted in 1981 (Barnes, 1994:2). Whereas the DPI definition identified disability as 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' I removed the term 'normal' from the affirmative model definition. As numerous disabled writers have observed, normality is a problematic concept. What remained, though, was the identification of disability as an unequal social relationship.

Where the proposed affirmative model significantly diverged from the social model was in its definition of impairment. It included no mention of 'functional loss', 'individual limitation', 'lack' or 'defect', all heavily loaded terms used in the definitions of UPIAS (1976) and DPI (1981). Rather, impairment was simply represented as a characteristic of human difference.

There is room within this definition both for feminists' recognition of the sometimes painful realities of embodied experience and for disability arts' claim to self-respect and validation of identity (Cameron, 2008:25).

While I recognise that some of my concerns expressed in *Further Towards An Affirmation Model* were answered in Swain and French's *Disability On Equal Terms*, I would still argue there is a need for definitions. Definitions enable us to succinctly express what is being

described rather than having to revisit starting points every time we attempt to explain meanings. As Mike Oliver observes, ‘models are ways of translating ideas into practice’ (Oliver, 2004:19) and I believe there is a need for the affirmative model to be forged as a practical tool. Whereas my 2008 definitions were tentatively suggested before I carried out my PhD research, the definitions I propose in this dissertation are grounded in the accounts of the sixteen disabled people I interviewed.

Chapter 2: What's the use of disability identity?

Introduction

I begin this chapter with a description of my own experience as it relates to disability identity. While my intention by this is primarily to demonstrate openness about my own position in relation to my research, I consider other purposes will also be served. As well as throwing light upon ways in which individual experience is always situated within wider structural contexts this offers an illustrative explanation of the value of taking on disabled identity as an empowering means of making sense of the world.

Accepting that disability identity is an unsettled issue, I then move to consider and address Tom Shakespeare's argument that disability identity can be associated with victimhood. I conclude by suggesting that a clarified affirmative model will progress discussion in this area.

Reflection

Critical social research should be reflective, so part of any analysis should be a reflection on the position from which it is carried out (Chouliaraki and Fairclough, 2005:66).

While there has been much criticism within Disability Studies of traditional 'objective' research carried out with disabled people (Barnes and Mercer, 1997), and while I believe that my own experience as a disabled person adds authenticity to this work, I do not suggest that this allows an unexamined approach to my own involvement within this research. As Colin Barnes and Geof Mercer have noted, disability research must not deteriorate into propaganda: it must be politically committed but rigorous (Barnes and Mercer, 1997:7). Ayesha Vernon has emphasised the need for reflexivity for those researching 'from the inside' as:

the closer our subject matter to our own life and experience the more we can expect our own beliefs about the world to enter into and shape our work, to influence the very questions we pose and the interpretations we generate from our findings (Vernon, 1997:159).

Knowledge is always socially situated within discourse and reflects ideological positions and assumptions. I do not regard closeness to my research area as a limitation, but I do feel that it needs to be made clear.

Personal Experience

On April 6, 1974, aged nine and on holiday in Yugoslavia with my family, on my way with my older brother to the beach opposite the camp site we were staying at, I was knocked down by a car travelling at 40 mph. I spent eighteen days in a coma, during which forecasts were made that I would either die or would never again see or hear. I acquired brain damage which caused slowness of speech and paralysis of both hands, as well as a badly fractured right knee. Repair of the knee was delayed because surgeons would not operate while I was in a coma. Surgery did not, in fact, take place till almost a month after the accident, after I had been moved to the British army hospital in Germany close to where we lived. The damage was compounded by the fact that, after this delay, my knee had begun to set and had to be broken again before being operated on.

As I remained in hospital over the next several months I was in no doubt that one day I would eventually be 'better'. I was encouraged to be 'a brave soldier' and told that, if I kept on working at my recovery, one day I would be fully fit again so nobody would be able to tell I had been in an accident. I set as my aim the day I would be recognised as normal. Not, I think, that I considered myself as anything other than normal, I just saw myself as having been involved in a bad road accident. I worked at my exercises to regain use of my hands, to gain strength in my legs, to become able to speak more quickly.

The first time it was suggested to me I was disabled was during the following year, after we had moved back to Britain. A boy at school named Derek Alcock asked me if I was physically handicapped. I considered the fact that I had been physically damaged and replied yes. He asked me if I was mentally handicapped. I considered the fact that I had received brain damage and again replied yes. This caused Alcock and his friends great amusement. At home that evening I asked my mother whether I was handicapped, physically or mentally. She replied by telling me no, of course not.

This I recall as having made a particular impact on me at the time. I was not handicapped. I had been in a road accident and had received very serious injuries, but I was getting better. One day I would be completely better and the whole thing could be forgotten. But I was definitely not handicapped.

I was turned down on grounds of fitness for attendance at Queen Victoria School in Dunblane, an army boarding school for sons of Scottish servicemen attended by both my brothers. In 1976 I started at the Royal Grammar School in High Wycombe, a state grammar, as a boarder. While the consequences of my accident impacted on me in various ways – I

was excused from rugby, I was punished by the music teacher for persistent lateness in getting to his class after the p.e. lesson (it took me longer to get changed back into school uniform) - most people accepted me as I was, or at least did not make an issue of my impairments. I had friends, I got on with things, I enjoyed mucking about. During my second term a boy named Ralph Bullock, a 4th Year, joined our dormitory. Bullock found entertainment in mimicking my speech, and this became a regular after 'lights out' activity joined in by others. I would often end up in tears.

In school lessons, where much time was spent copying masters' scrawl from blackboards, I found myself unable to keep up with the rest of the class as a result of the slowness in my left hand, and what had to be copied out was usually wiped off before I had finished getting it down. I ended up trying to copy from the exercise book of whoever I was sitting next to, which inevitably caused friction. I eventually gave up bothering to try and spent lessons concentrating upon finding other forms of diversion, usually involving trying to entertain the rest of the class. I began to find myself a frequent visitor to the junior headmaster who would give me a stern talking to and ask what had become of the nice boy who had joined the school.

My attitude towards school and to life in general became progressively worse. While the term *cripple* was a fairly generally-used term of abuse, I would fight anybody who used the word to me. As the school placed high value upon physical achievement and prowess in sports, I found myself excluded from approved paths for gaining distinction, and resorted to making my mark in subordinate ways.

It was at the end of a class cross country race towards the end of 1977 that I came to the sudden realisation that I was never going to be better and that the day when nobody would ever be able to tell that I had been in an accident was never going to happen. That this *me*, the damaged *me*, was the only self I was ever going to know. All the rest of my class, who had reached the school gates long before I reached the top of Hamilton Road and came round the corner, were gathered to applaud my perseverance. I decided I was sick of it. I did not want to be known for my infirmities and would be known instead for being disruptive (Cameron, 2006).

Distancing myself from association with disabled people was not very difficult during my teenage years as I very rarely came into contact with anyone I would have considered disabled. Apart from one 6th former when I started in the 2nd year, I cannot remember a single disabled boy at the school during the years 1976-1982. As the school had a roll of

1100 boys from all over South Buckinghamshire each year this was not because it was a small school. Within a Tory-run county that still operated a tripartite system of secondary education there may have been disabled pupils at some of the secondary moderns, but as far as I know they usually went to segregated special schools.

In 1979 an American family with a son named Pete who had spina bifida joined the church my family attended. A number of days during the school holidays were what I considered to be ruined by arrangements made between mothers for me to go and spend the morning with Pete. It was suggested to me that I should have an understanding of Pete's situation and that therefore I should befriend him. As far as I was concerned this was completely unreasonable. He was disabled and I was not. I was taken to visit him several times but did nothing to encourage friendship.

The fact that I did not consider myself disabled did not, however, mean that I enjoyed being who I was. I became increasingly angry and negative, wishing uselessly that I had not stepped in front of that car. As far as I was concerned it was my impairments that held me back. At a time when it seemed most of my peers were busy getting off with girls (or were, at least, boasting about it), I was painfully aware that this was not happening for me. My first real intimate sexual contact occurred when I was seventeen when I was sexually assaulted by a man on a train. Smoking from the age of thirteen was, of course, an obvious form of rebellion.

1981 was the International *Year of the Disabled*. Stories about disabled people seemed rarely to be off the TV screen or out of the newspapers. Predictably, these were solid in representing disability as personal tragedy, to be triumphed over at a personal level and responded to with charity at a social level. My own rejection of disability identity at this time can be illustrated by reference to two events. In June I represented the school in a balloon debate against a nearby girls' convent school, appearing as Joey Deacon. Joey Deacon was a man with cerebral palsy who had been featured with condescending sentimentality on the children's TV show *Blue Peter* while publicising *Tongue Tied*, a book he had written about his life experience of institutionalisation. Quite vindictively, I played the character for laughs, to the amusement of most of the audience and the absolute fury of Mr Cuthbert, the master who had driven us in the school minibus to witness this disgrace. In December I published 250 copies of *A Tale of Christmas Cheer*, a story I had written with a friend, John Hussey, about a poor disabled boy, also named Joey, who is entrusted with a magical task by a drunken Father Christmas, to deliver presents to all the children of the world. This provides an opportunity for Joey to shine 'in spite of his awful and ever-increasing disabilities'

(Cameron and Hussey, 2001:16). Through his plucky courage and determination Joey succeeds and is rewarded by a good fairy who bestows upon him bounteous gifts:

“Oh,” Joey laughed, “I am so happy, how can I ever thank you enough?”

In fact he was so happy, too happy, his weak heart could not stand the excitement, and he fell over, dead. Everybody was most upset.

“Do not worry,” the angel said, “Joey is gone to a happier place. For all his life he was held back by his unfortunate disabilities. Now he is free.”

(Cameron and Hussey, 1981:20).

This story sold out in two days. Fifty copies were sold between assembly and morning break to girls at the Lady Verney High School. *A Tale of Christmas Cheer* was a very dark comedy, written with anger and bitterness. I would now perhaps suggest that at the time I was reacting against media portrayals of disabled people, but I did not have the experience to understand this. As far as I was concerned, disability was something to be laughed at. I had nothing to do with disabled people and they had nothing to do with me. Disability was their problem, not mine. I had just been knocked down by a car and that was different.

It was after I left school in 1982 that my father started suggesting I should register as disabled. This was something I reacted angrily against and refused to consider. I would not register disabled because *I was not disabled*. My father made this suggestion on various occasions during the next few years.

In autumn 1982 I spent a period in hospital having my left leg shortened to compensate for loss of growth in my right. Having engaged in several lengthy conversations with the lady from The Church Army who brought round the book trolley, I made what, for me, was a very important decision. I decided I could either carry on being cynical and negative, of no use to anyone, least of all myself, or I could try and use my experience to help others going through similar situations. I saw myself working *with* disabled people, *helping* disabled people, but certainly not *as* a disabled person. I aspired for a short while after this to become a social worker.

A number of disabling experiences stand out in my memory from my time as a Social Administration student at Brighton Polytechnic. Enquiring about holiday jobs at a Wimpy burger bar where staff were being recruited, I was told bluntly by the manager that he would not consider me “Because this is a fast food restaurant and you’re not fast”. A girlfriend’s

mother did her best to discourage the relationship, describing me as ‘half-baked’. To be refused service in bars when I was completely sober “Because you’ve had enough to drink already,” was not unusual.

After gaining my degree in 1986, I got a job in Slough as a residential social worker with young adults labelled as having learning difficulties. This job involved my first real contact with disabled people. I recall particularly a number of occasions when milkmen came to collect their money or when workmen came to work around the building. I would answer the door. “Can I help you?” I would ask. “Can I speak to a member of staff, please?” came the response. “I am a member of staff,” I replied. After a moment’s hesitation the milkman or workman would say “Yes, that’s right... but can I speak to one of the nice ladies?” The mother of one of the residents asked the manager who ‘the new boy’ was, referring to me. The organisation was in financial trouble and the residential home closed down shortly afterwards.

A period of unemployment in Slough had such a dispiriting effect that I eventually conceded to my father’s suggestion to enquire about registering disabled. This was done with the expectation I would get told no, I was not disabled, so I could finally get him to stop going on about it. I turned up at the disablement resettlement officer’s office at the Job Centre and announced “I’ve come to see about registering as disabled,” expecting this to be the start of a formal process involving having to appear before a medical tribunal. She took one look at me and said “Yes, you’re disabled, all right.” I left her office five minutes later with a green card and a registration number, SLR8812. I emerged from her office a disabled person.

It was with some surprise that I woke up the following morning to discover I was the same person I had been before I was disabled or, more specifically, before I was registered disabled. I came to own the word, but to regard it as saying something about me and my impairments. It was part of a process that involved an increasing acceptance of myself as I was, but that still remained rooted in a medical model understanding.

Registering as disabled did the trick in employment terms and I found myself a fortnight later commencing employment as a clerical officer at Slough DHSS. This was, I soon discovered, a tedious bureaucratic job I had neither interest in nor aptitude for. I left the job at the earliest possible moment to return to higher education.

In Newcastle upon Tyne I encountered the disabled people’s movement and underwent what I consider one of the most important and positive changes in my life in terms of the way I relate to myself. In a pub on Newcastle Quayside in April 1992 Geof Armstrong, the director

of the National Disability Arts Forum, outlined to me the distinctions between the medical and social models of disability. In many ways this was like a religious conversion experience. As has been described in personal accounts by many disabled people (e.g. Morris, 1993), it was as if a light went on. The idea that disability did not describe me as an impaired individual but signified an oppressive relationship enabled me to make a new sense of my own experience. For the past eighteen years I have worked within the disabled people's movement as a disabled person, as somebody who is comfortable to identify as disabled.

This is not, however, a 'happily ever after' story. Taking on a disability identity is not a once-and-for-all event. As Ken Plummer points out:

Everywhere we go, we are charged with telling stories and making meaning – giving sense to ourselves and the world around us. And the meanings we evoke and the worlds we craft mesh and flow, but remain emergent: never fixed, always indeterminate, ceaselessly contested (Plummer, 1997:20).

Identifying as disabled is not a decision that suddenly somehow means everything is all right, but involves a new understanding of the relationship between the self and the physical and social contexts in which the self is located. It makes possible different stories, which identify as the site for struggle the environment in which the self lives rather than the physicality of the self, but it does not imply there is no longer a need for struggle. When, for example, in 1994, an official from the Sports and Arts Foundation pressed £1 into my hand and earnestly told me to buy some chocolate, I was able to understand and explain the oppressive assumptions underlying his behavior. Politely but firmly declining his offer, I was able to walk away (laughing at him), recognizing the problem in this situation as his rather than mine.

Disability identity and victimhood

A position recently proposed by Tom Shakespeare, and regarded as controversial within Disability Studies (Beresford, 2008), suggests that disability identity can be associated with victimhood, explaining any problems that individuals may encounter, or failure they experience, as resulting 'from oppression, not from any fault of their own' (Shakespeare, 2006:80). Using the social model, Shakespeare argues:

is a powerful way of denying both the relevance and the negativity of impairment. Activists can maintain that their problems are not due to their deficits of body or

mind, but to the society in which they live. By combining with others who share this belief, their own self-image is reinforced, and they can achieve solidarity and self-respect (Shakespeare, 2006:80).

Shakespeare argues that the identity politics of the disabled people's movement has depended on strengthening the emphasis upon differences between disabled and non-disabled people, strengthening the coherence and separateness of the disability group, and contrasting disabled and non-disabled people in a way that views the latter group as oppressive and hostile. Disability identity, he contends, rather than being a means to an end, has become an end in itself. It involves an inward-looking group approach rather than an approach which seeks to build bridges with other groups and to achieve real inclusion for disabled people within society (Shakespeare, 2006:80).

At the same time, Shakespeare writes approvingly of people with impairments who disavow identification as disabled. Citing research carried out by Nick Watson with twenty-eight disabled people in Scotland, he points out that

Despite daily experiences of oppressive practices, only three of the participants incorporated disability within their identity. Instead, they normalised their experience of physical limitation. They were all able to describe experiences of discrimination. But they rejected a political identity as disabled (Shakespeare, 2006:74).

Shakespeare highlights the wish of Watson's research participants to assimilate with the mainstream and negate a demeaning difference. Many people, he argues,

do not want to see themselves as disabled, either in terms of the medical model or the social model. They downplay the significance of their impairments... They see themselves as 'really normal', refusing to allow disability to dominate their lives (Shakespeare, 2006:74).

While acknowledging the individualism inherent in this approach, and the fact that it may overlook the problems of discrimination and prejudice, this is presented as 'surely a legitimate alternative to a minority group approach' (Shakespeare, 2006:74).

In the context of my thesis and of my own experience described above, I find Shakespeare's argument unconvincing. The position of the disabled people he refers to sounds similar to the position I held between my road accident in 1974 and coming into contact with the disabled people's movement. Shakespeare acknowledges that they recognise 'daily experiences of

oppressive practices', but almost seems to put forward as legitimate the suggestion that if disabled people do not like the word 'oppressed' and do not want to call themselves or think of themselves as 'oppressed' then they will not be 'oppressed'. If disabled people do not like the word 'disabled', Shakespeare argues, it is a valid position to refuse personal association with the word.

One of Shakespeare's key claims for questioning the value of the social model and disability identity is that in the three decades since its development as an idea it has never progressed beyond being a minority position:

The implication of early disability activism that people with impairments were oppressed and that salvation lay in collective identification and mobilisation has proved over optimistic: only a tiny proportion of people with impairments have ever signed up to the radical campaign and many have actively disowned it (Shakespeare, 2006:74).

This can, however, be read rather differently. That only a minority of disabled people have actively identified with the disabled people's movement, or have taken on a political disabled identity, can be regarded as an indication of the depth of disability as cultural oppression. Shakespeare's argument can be likened to a suggestion that because more women read *The People's Friend* or *Take A Break* than read Ann Oakley or Judith Butler, feminist perspectives are therefore invalid.

As a disabled person I have found the social model bears a truth previously unavailable to me as a narrative on which to build a personal and social identity. The social model is a reasonable proposition. Media portrayal, and representation by writers like Tom Shakespeare, of this position as radical does not make it radical, but reflects a conservative position. Lack of media support for this position limits the possibilities for this to be taken up by disabled people.

In the research paper cited by Shakespeare above, Nick Watson states that:

Being disabled, for many of these informants, is not about celebrating difference or diversity, pride in their identity is not formed through the individuals labelling themselves as different, as disabled, but it is about defining disability in their own terms, under their own terms of reference (Watson, 2002:521).

Returning to Elias' and Bourdieu's positions outlined above, the weakness in Watson's position is clear. Social reality is never defined in our own terms as if these are original to us,

but is experienced in the terms of specific historical contexts and discourses which situate us. Anthony Giddens argues that:

social circumstances are not separate from personal life, nor are they just an external environment to them. In struggling with intimate problems, individuals help actively to reconstruct the universe of social activity around them (Giddens, 2003:12).

In a context where reflexivity is a social requirement of the individual – in which the individual has no choice but to live ‘a biography reflexively organised in terms of flows of social and psychological information about possible ways of life’ (Giddens, 2003:14) – it is little surprise that disabled people, even the majority of disabled people, should choose to view themselves as individuals rather than as members of a stigmatised group. It is little surprise that in a social world where impairment is regarded as a mark of inferiority, disabled people should ‘downplay the significance of their impairments’ (Shakespeare, 2006:74) and seek to become integrated into the social mainstream without their impairments being noticed. What I do find surprising is the suggestion that the discovery that people with impairments answer the question “How shall I live?” with the answer “Not as a disabled person if I can help it,” should be considered a new insight, and a valid response to the experience of disabling oppression.

Conclusion

To be wholly or in part ‘out of place’ everywhere, not to be completely anywhere (that is without qualifications and caveats, without some aspects of oneself ‘sticking out’ and seen by others as looking odd) may be an upsetting, sometimes annoying experience. There is always something to explain, to apologise for, to hide or on the contrary to broadly display, to negotiate, to bid for and to bargain for; there are differences to be smoothed or glossed over, or to be on the contrary made more salient and legible (Bauman, 2006:13).

I would suggest that Zygmunt Bauman’s statement above is a fairly accurate summation of what happens as part of everyday experience for most disabled people, and explains why identity reappears so frequently as a problematic theme in their lives.

Fundamentally, I would argue, a choice has to be made between whether to try to deflect attention away from or unashamedly display those aspects of the self considered abnormal. I would characterise the first position as one which rejects disability identity and seeks to

cover up the significance of impairment in everyday life and relationships. Glenda Hyatt, for example, remarks that:

People have expected me to take the nicely paved path laid out for the disabled. They expected me not to try, not to accomplish, and not to succeed. That map was tossed out long ago. I have followed my own path as a person, a woman, who happens to have a physical disability (Hyatt, 2008:unpaged).

It will become clear later, in my discussion of disability as role, why I consider Hyatt's disavowal of 'the nicely paved path laid out for the disabled' just as predictable and socially acceptable a response to the experience of impairment as the passive lifestyle she rejects. This is a position which necessarily involves an attempt to live with a sense of one's own difference as undesirable misfortune, but hopes to compensate well enough so that others will tolerate or overlook impairment. I use the word *necessarily* because this position offers no alternative with which dominant medical model assumptions can be challenged.

The second position I would characterise as one which identifies disability as structural oppression and embraces disability identity. This involves what Max Frisch has termed 'the rejection of what others want you to be' (cited in Bauman, 2006:38). I would argue that taking on disability identity offers the only real alternative to complying with conventional expectations and gives a critical vantage point from which to regard reality. If identity is a storyline we use to comprehend and negotiate our place in the world and to reflexively determine our own experience of the world as it is given to us, rejection of disability identity involves deprivation (whether self-willed or through unawareness of its existence or purpose) of a valuable sense-making tool.

In my research I attempt to develop new insights into people with impairments' self-perceptions and about ways they relate to the idea of disability. This is not, however, a rhetorical exercise attempting to demonstrate that life is easier or better with the social model. Whereas in the past attempts to include impairment in the analysis of identity have been resisted as a threat to the unity of the disabled people's movement (Scott-Hill, 2004:92), I suggest a clarified affirmative model offers a fresh insight into identity issues rooted within individual and collective experiences of living with impairment in a disabling society. What I have attempted is to ground the affirmative model within the experiences of the sixteen disabled people I have talked with. This involves shifting the affirmative model from being a set of statements inferred from the output of the disability arts movement to being a model that can be shown to hold good when measured against the experiences of disabled people, whether in terms of positive or negative experience.

Chapter 3: Methodology

Why am I researching this?

While I have already outlined why disability identity is an issue that interests me, I need to say more about my interest in the affirmative model. At the time of the publication of *Towards an Affirmation Model* in 2000, I was working closely with John Swain at Northumbria University and enjoyed many discussions with him about this idea in the bar at Coach Lane campus. Since then I have considered that it holds promise as a tool of use to disabled people in making sense of personal disabling encounters in everyday life comparable to the social model as a tool for making sense of structural disadvantage. I argue here that a framework is needed to allow disabled people to talk of this personal experience – while still recognising disability as a structural relationship - and that the affirmative model could provide a useful tool for making this possible.

If theories are stories about the way the world (or some portion of it) works, then they are always in a state of revision, and there are always other, alternative stories that could be told (Esterberg, 2002:9).

While Mike Oliver has stated emphatically that he does not regard the social model as a theory (Oliver, 2004:9), the social model is at least a theoretical abstraction. It is certainly the foundation of a story about the way the world works. It seemed to me that the affirmative model was another story, a story which built upon the social model but was able to say something about the reality of being disabled that the social model missed.

The affirmative model was further discussed briefly in the chapters ‘Celebrating difference?’ in *Controversial Issues in a Disabling Society* (Swain, French and Cameron, 2003) and ‘Whose Tragedy? Towards a personal non-tragedy view of disability’ in *Disabling Barriers – Enabling Environments* (Swain and French, 2004). On a personal level I considered the affirmative model a very positive development in Disability Studies theory but through discussion with other disabled people, principally in the context of delivering training for Disability Equality in Education, I was aware that not everybody shared this view. Some thought it was an unnecessary diversion, adding nothing the social model did not already say. Others were unclear about what the affirmative model actually *is*. I sensed this might be the result of a lack of clarity in Swain and French’s writings on the subject, or that it may have been their intention to avoid trying to pin down meaning on this matter.

There was not a set of definitions provided, as there are in both the medical model (through the ICIDH definitions) and the social model (through the UPIAS and DPI definitions) so that one could clearly state, in outlining the affirmative model, the meaning of the terms impairment and disability. As far as I could read in the emerging literature and from occasional telephone conversations with John Swain over the next few years, neither he nor Sally French seemed to see a requirement to go further in clarifying their idea. I felt this was likely to mean that a good idea would remain underdeveloped, and considered this regrettable.

When the opportunity arose to apply for this PhD studentship I saw this as a chance to make an intervention within the situation. I considered that an investigation which asked questions of mainstream media representations of disability in the light of the affirmative model could provide the focus for the further development of the model. My initial proposed research title in my application to Queen Margaret University College in early 2006 was ‘Another Way of Being: An Enquiry into the Development of an Affirmative Model as a Tool for Analysis of the Social Construction of Disability’. I stated my belief that ‘the affirmative model holds promise as a tool for the analysis of the social construction of disability in the media’ and suggested that through a variety of methodological approaches – including analysis of audience reaction to a variety of contemporary cultural texts and semi-structured interviews with research participants on the meanings of texts, a defined and sharpened affirmative model could be tested for its validity. I suggested that the establishment of the affirmative model ‘as a tool for the analysis of disability representation may be of value, not only to disabled people themselves in the struggle for social equality, but also more broadly as an additional piece of apparatus within Cultural, Media and Disability Studies’.

Turning the idea into a question

It became clear that, as far as carrying out research for a PhD was concerned, I would run into problems if my intention was to start with the theory (the affirmative model) and, without subjecting this to critical enquiry, to simply try to demonstrate its validity by drawing observations supporting it from the empirical world. Certainly this would prohibit a purely inductive approach, one which involves starting off with an examination of the social world and developing a theory consistent with what is discovered (Esterberg, 2002:7). Rather, it became clear that what I was seeking to do seemed to require a research process involving deductive reasoning. Kristin Esterberg has described this type of research as involving several stages, including:

- developing a theory, usually based on the body of research that other scholars have already conducted
- operationalising the theory by developing hypotheses and choosing a representative sample and a research design
- carrying out the research, collecting data and conducting analyses
- drawing conclusions about the plausibility of the theory on the basis of whether or not tests confirm the theory

(Esterberg, 2006:6).

Issues here arose in that, firstly, I already had a theory (the affirmative model) and, secondly, the qualitative approaches I proposed using did not easily match with the methodological requirements of deductive reasoning. As well as seeking to establish the validity of the affirmative model through critical analysis, I wanted to clarify it in the light of disabled people's responses to cultural texts and media representations of disability. That is to say, the development of the affirmative model would rely on the data I produced through interviewing disabled people. In Esterberg's words, what I wanted to create was *an ongoing dialogue between theoretical concerns and empirical evidence* (Esterberg, 2002:8). This implied the necessity for moving back and forward between inductive and deductive reasoning, a practice Esterberg argues is legitimate and quite common (Esterberg, 2002:8).

As my thinking about my research developed my area of enquiry began to take the form of a question: *Does anybody like being disabled?* This seemed to me a two-sided question. If it is read from a dominant cultural position it could be seen as rhetorical: if disability is perceived as individual tragedy, the answer will likely be no, this is an experience nobody would willingly embrace. If it is read from a perspective informed by the social model, its meaning is changed: if being disabled involves being oppressed within a disabling society, the answer is still no, but for different reasons. There is something hidden in here, and that is the difference between living with impairment and being disabled. When the distinction between these models is made, the proposition *nobody likes being disabled* is different to the proposition *nobody likes living with impairment*. It seemed that this question afforded an opportunity to explore some of the areas of difference involved in these two ways of looking. I hoped the answers I might find in exploring this question would offer insight into ways in which the affirmative model could be clarified.

At the stage of submitting a developed proposal I had identified my research as involving a critical exploration of impairment, identity, media and everyday experience in a disabling society. I had identified as my research aim the exploration of tensions for disabled people in the construction of positive identities in contexts in which self-understanding is shaped both by social structural relations of inequality and unique individual experience.

In order to address this aim I identified five substantive questions:

- Is the social model of disability adequate as an explanatory tool for the description and analysis of the everyday experience of living with impairment in a disabling society?
- In what ways do media representations of disability impact on the identities of disabled people?
- How useful a concept is 'disability identity' as a tool to people with impairments in making sense of their own experience?
- Is the affirmative model an adequate explanatory tool for analysis of the cultural construction of disability?
- Is the affirmative model an adequate explanatory tool to account for both recognition and redistribution issues in relation to the experiences of disabled people?

What is my thesis?

Richard Hamer, Director of External Affairs for Scotland's largest disability charity, Capability Scotland, posted a statement on *The Scotsman* newspaper's *Opinion* webpage in 2009, saying that:

Disabled people's access to the world around them has improved markedly since the Disability Discrimination Act was introduced in 1995. You only need to walk along Princes Street to see the difference. Following the removal of steps, the automation of doors and introduction of lifts, amongst other improvements, you'll see far more disabled people shopping alongside the rest of the general public. However, there is still a long way to go – not only in removing physical barriers but also in changing attitudes (Hamer, 20.02.2009).

Hamer expresses a view here that ‘things are getting better for disabled people’. He draws attention to a number of access improvements that have been made to shops in Edinburgh’s Princes Street in order to demonstrate his point. He also acknowledges that there are physical barriers still to be removed and a continued need for attitude change (presumably towards disabled people).

As John Swain and Paul Lawrence have pointed out, organisations of disabled people have rejected attempts to change attitudes, through programmes such as disability awareness training, as being misconceived and misdirected (Swain and Lawrence, 1994:92). The three components of attitudes (cognitive, emotional and behavioural) are loosely related and do not necessarily have direct impact on each other. Thus, while Hamer can talk about the need to change attitudes, he presumably sees no contradiction between this and statements on Capability Scotland’s website such as:

Your small change will make a big change!

By having one of our collection boxes in your business or workplace, your customers and colleagues can start making a difference to the lives of disabled adults and children right now... When the box is emptied we will give you a ‘thank you’ receipt displaying the amount collected from the box. This thanks everyone and lets them know how valuable their support is (Capability Scotland, 2010)

A clearer endorsement of the charity model of disability would be hard to find. Liz Carr has provided a detailed critique of the way in which large charities like Capability Scotland have repackaged charity to harness the ideas of the disabled people’s movement. She argues that this strategy strengthens the charity model and charities’ credentials in speaking on behalf of disabled people and rationalising continued segregated provision (Swain, French and Cameron, 2003:92). Hamer can, in this way, talk approvingly in *The Scotsman* about access improvements, drawing publicity to Capability Scotland, while at the same time the organisation runs two segregated schools for disabled children.

Insofar as disability is thought of socially, culturally, or historically, it is usually represented in terms of improvement. But, as Ellen Barton observes:

disability also must be defined as a more complex social construct, one which reflects not a benign evolution of acceptance but a dynamic set of representations that are deeply embedded in historical and cultural contexts (Barton, E.L. 2001:169).

While barriers to access to shops on Princes Street may be being removed, there exists an ambiguity around meaning and an entrenchment of perceptions that continue to reflect a medical/personal tragedy model of disability. For example, Jane Campbell argues that the current debate on legalising assisted suicide carries a set of implicit assumptions rooted in fears of pain, of disability, and of being a burden to others (Campbell, 2006(a): unpagged). She has stated that the background noise to current discussions around assisted suicide:

is reinforcing negative perceptions of disability. It feeds into desires for a body beautiful and a perfect life untroubled by illness. It promotes premature death as a choice option, especially for people with severe disability or terminal conditions

(Campbell, 2006(b):14)

My thesis is that while certain barriers to participation in ordinary community life may be being removed, perceptions of impairment as something ‘wrong’ with the bodies of disabled people, and as a signifier of personal tragedy, remain embedded in dominant disability discourse. There is a structural purpose to the continued representation of impairment as unfortunate aberration from normality rooted more deeply than can be addressed by simple injunctions to ‘change attitudes’. Subjection to disabling discourse on an everyday basis can have a confusing and demoralising impact on disabled people’s self-perceptions. The affirmative model holds promise as a tool for use in reflecting on and addressing this subjection. To this purpose, the affirmative model requires clarification.

Why critical social research?

At the heart of critical social research is the idea that knowledge is structured by existing sets of social relations. The aim of a critical methodology is to provide knowledge which engages the prevailing social structures (Harvey, 1990:2).

As Lee Harvey has explained, critical social research is not constrained by its data collection methods. It is not these that characterise critical social research so much as the ways in which data are approached and the framework within which they are analysed. Critical social research does not concern itself with discovering the ‘causes’ of observed social phenomena

nor is it satisfied with the interpretation of the meanings of social actions. Its fundamental aim is to destroy the illusion of observed reality (Harvey, 1990).

The substantive issue I want to address concerns the reasons why people with impairments often find it difficult to feel positive about being the people they are. This will involve an attempt to penetrate both the outward appearances of what is going on and participants' surface level responses.

What I was looking for, when initially trying to decide upon a framework for structuring my research, was a comprehensive methodological approach through which I could deconstruct the personal tragedy myth and, having subjected it to critical exploration and evaluation, propose a clarified affirmative model as a new construction 'which seeks not to demonstrate final absolute truth, but to present an approximate reflection of reality which is subject to continuous change' (Harvey, 1990:197).

Before elaborating on why Harvey's critical social research methodology suggested itself as the approach most likely to yield useful knowledge in terms of this issue, I will briefly outline reasons which led me to reject other approaches to qualitative research.

Why not ethnography?

Ethnography involves an extended observation of the group, most often through participant observation, in which the researcher is immersed in the day-to-day lives of the people and observes and interviews the group participants. Ethnographers study the behaviour, the language, and the interaction among members of the culture-sharing group (Creswell, 2007:68).

I was initially attracted to the idea of carrying out my research as an ethnographic study because of the potential I saw for gathering thick data on the day-to-day experiences of disabled people as they occurred. This would have allowed me the opportunity to make clear my political commitment as a disabled person siding with the disabled people participating in my research (Becker, 1991). However, there were a number of considerations which led to my rejection of this approach. These related to issues concerned with identifying a group.

Talking of the disabled community does not describe a collective of people who necessarily spend a lot of time 'hanging out' together. While many disabled people do spend a lot of time together in special schools, day centres, supported employment, and so on, I identify these in terms of what John Fiske has described as *stations* rather than as *locales*:

A station is both a physical place where the social order is imposed upon an individual and the social positioning (stationing) of that individual in terms of social relations... Constructing a locale involves confronting, resisting or evading imperialising power (Fiske, 1993:12).

Acceptance that one belongs in 'places like these' with 'others of my kind' involves an acknowledgement of dominant disability discourse. Outwith these stations, though, association with other disabled people is typically shunned in order to evade association with what is perceived to be a devalued group, again an acquiescence with dominant disability discourse (Goffman, 1976). Donna Reeve describes the situation of disabled people who have learned that it is best 'trying to excel and pretend that there [is] nothing actually wrong' (Reeve, 2006:103). The term 'disabled community' cannot refer to all disabled people if disabled people spend their time avoiding each other or disassociating themselves from this identity.

It would be possible to consider the disabled community in terms of the disabled people's movement, if our understanding of community is one that is grounded in shared understandings as a result of some unifying characteristic (of being disabled by society) (Barnes, 1997:9). However, this community is not one sustained by daily face-to-face interaction (unless we consider small groups, such as staff groups in small voluntary organisations) so much as through monthly or bi-monthly meetings, cultural events and so on.

In relation to my research, to have looked to work with a group of disabled people in a station, where I could have counted on having access to the same group of people on a regular basis, while it may have made an interesting study would not, I felt, be likely to produce the diversity of responses I hoped to gather. It might have been revealing in terms of establishing why disabled people comply with dominant disability representations, but it would have given a narrow answer to my question. Correspondingly, to have sought to work with a group from the disabled people's movement would be likely to have resulted in shared rather than divergent perspectives on the issues I wanted to explore.

Finally, whereas ethnography typically focuses on setting the accounts of individuals in the context of their own culture and culture-sharing group, my aim involved setting these accounts in the context of an oppressive dominant culture (Creswell, 2007).

Why not grounded theory?

The intent of a grounded theory study is to move beyond description and to generate or discover a theory, an abstract analytical schema of a process... Participants in the study would all have experienced the process, and the development of the theory might help explain practice... (Creswell, 2007:62).

The basic problem preventing me from carrying out my research as a grounded theory study was, as I have indicated above, that I already had a theory, the affirmative model. Processes and issues I would have looked to address within such an approach would have included those by which people with impairments are turned into disabled people and those of being subjected to endless negative representations. While the insights generated this way would have provided much interesting material with which to address to my research question, my aim of clarifying the affirmative model would not have been possible.

(Having carried out analysis of my research since I made the above statement I realise that, in grounding my affirmative model definitions within insights and perspectives offered by participants in my research, I have constructed a grounded theory. My analysis has addressed more or less exactly the processes identified here. However, I maintain that when I began the process adopting a grounded theory approach seemed inappropriate as, in certain respects, my theory was already known.)

Why not narrative research?

The procedures for implementing this research consist of focusing on studying one or two individuals, gathering data through the collection of their stories, reporting individual experiences, and chronologically ordering the meaning of those experiences (Creswell, 2007:55).

While a narrative study appealed in terms of the depth it would allow in exploring personal experiences relating to a very small number of disabled people, including ways in which they are situated in interactive encounters and their own interpretations of these encounters, I felt this could be done more effectively by using a larger number of participants. I considered that to develop a narrative approach would be to restrict myself in terms of collecting a diverse range of perspectives and perhaps compromise the validity of my conclusions. Generalisation upon the basis of the experiences of one or two people might be difficult and unconvincing.

Why not case study research?

Case study research is a qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information... and reports a case description and case-based themes (Creswell, 2007:73).

My principal reason for rejecting a case study approach was that this suggested a top-down, objectifying and controlling approach. The idea of turning disabled people into 'cases' also had too many associations with medical and social work practice for me to feel comfortable with. While I am aware that other *bounded systems* may have been identified as cases to be studied, for instance I could have explored the reactions, feelings and thoughts of disabled people towards a particular practice, event or series of representations, I felt that this approach would probably be more appropriate for a descriptive rather than an exploratory study.

Why not phenomenological research?

Phenomenologists focus on describing what all participants have in common as they experience a phenomenon... The basic purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence... This description consists of 'what' they experienced and 'how' they experienced it (Creswell, 2007:58).

Of the five qualitative approaches suggested by Creswell, a phenomenological approach appeared to offer most in terms both of answering my research question and allowing me to clarify the affirmative model. The phenomena under consideration would have been 'being disabled' and the description would have related to participants' accounts of their own understanding of this experience. Questions that suggested themselves included: what is it like to be disabled? What is the nature of the lived experience of being disabled? What does it mean to have an identity as disabled? How is it possible to identify positively as disabled? From the universal essence would have emerged the clarified affirmative model.

The problem I stumbled over, however, related to the need emphasised by Clark Moustakas for phenomenological enquirers, in order to fully describe how participants view the phenomenon in question, to 'bracket out' their own experiences:

We set aside our prejudgements, biases, and preconceived ideas about things. We ‘invalidate’, ‘inhibit’, and ‘disqualify’ all commitments with reference to previous knowledge and experience (Moustakas, 1994:85).

There seemed to be a contradiction between the process of bracketing and maintaining a political commitment to carrying out research as part of the emancipation of disabled people.

I was also unconvinced that the phenomenological practice of considering each experience ‘in its singularity, in and for itself’ (Moustakas, 1994:34) would offer the kind of insight I was after.

The phenomenon is perceived and described in its totality, in a fresh and open way. A complete description is given of its essential constituents, variations of perceptions, thoughts, feelings, sounds, colours and shapes’ (Moustakas, 1994:34).

This is to say that I felt that emphasis upon the minutiae of individual experience was likely to prohibit an effective critical contextualisation of that experience as part of a social experience. This phenomenological approach to developing knowledge clearly has different aims from Harvey’s critical social research, which involves

the penetration of outward appearances through the methodological process of abstraction from the general category to the concrete historically specific which is then related to the whole (totality). Comprehension of even the most apparently simple form requires a grasp of structure (made accessible through abstraction from the general category), and history (Harvey, 1990:197).

It is for these reasons that I rejected the qualitative methodological approaches identified above as frameworks within which to organise my own research. There are two points, though, that I wish to make in relation to these before I move on. The first is that I am aware that my reasons for deciding against each were made on the basis of only fairly superficial understanding and after hunting through a necessarily limited number of research methods textbooks. But decisions throughout life have to be made on the basis of partial knowledge. The second point is that the fact that I have rejected these approaches as overarching frameworks does not mean that I do not intend to draw upon perspectives generated within each: for example, in making use of Schutz’s ideas of imposed and intrinsic relevances, I draw upon phenomenological insight.

Critical social research, abstraction and deconstruction

Examine how the concept has been used and then ask what the underlying assumptions are that inform this usage and how it relates to the general area of enquiry. The relationship between the abstract core concept and the area of enquiry should be investigated at the level of general abstractions and in terms of concrete empirical relations. Ask what appears to be going on at the abstract level and how this is manifest in concrete situations (Harvey, 1990:30).

Conventional thought identifies impairment and disability in terms of loss, lack, restriction of ability or as personal tragedy. Through an ongoing process of abstraction and deconstruction I have reconstructed an alternative perspective. I have problematised the ideology embedded in prevailing conceptualisations of disability. I have related my core abstraction, disability, to the social totality to see if it reveals further the workings of the totality. I have used empirical data gathered from the research participants to elaborate this relationship. I have aimed to develop a new account of the social processes and structural relations involved in the development of the identities of people with impairments in a disabling society. In doing this, I have aimed to develop a deeper understanding of the issues at hand which goes beyond surface appearances and relates the parts to the whole. It is this deeper understanding I have used to clarify the affirmative model.

Critical social research and data collection

It is neither data collection devices nor analytic techniques that characterise critical social research so much as the way that data are approached and the frameworks within which they are analysed. Harvey indicates that a wide range of data collection tools are appropriate to use, including semi-structured, unstructured and in-depth interviewing as well as observation, both participant and non-participant (Harvey, 1990:196). It is, in fact, these tools that I used for data collection.

Identifying participants

Because Swain and French had initially drawn inspiration for the affirmative model from the values and work emerging from the disability arts movement (Swain and French, 2008:65), I considered it important to involve at least a small number of participants in my research from this movement. I therefore asked Charles and Lola if they would be interested in participating. I had met Charles on several occasions since 2002 through delivering training

events for disabled peoples' organisations and had also seen him perform at a number of disability arts events. I had first met Lola through a disabled colleague from London who had told me about her short stories.

I was seeking to identify between ten and twelve participants, each of whom I intended to meet across a series of data gathering sessions (outlined below). Having identified two disabled artists I wanted to identify the remainder of my participants from the wider disabled community. On 17 July 2007 my letter asking for participants to take part in my research was published as an e-bulletin by Inclusion Scotland, the national campaigning organisation of disabled people.

In this letter (Appendix A) I introduced myself as a disabled PhD researcher at Queen Margaret University, Edinburgh, looking for 10-12 disabled people anywhere in Britain who would be interested in taking part in a series of interviews on disability identity. I stated that this would involve talking about ways that people think about themselves, experiences that have led them to think the way they do, and messages about being disabled they have been given as members of families, communities, society.

I explained in the letter that I would like to involve:

- People who had really strong and positive disability identities, maybe activists involved in campaigning in the disabled people's movement
- People for whom being disabled is just a fact of life, something to get on with, but not really something to go on about;
- People who really hate being disabled and who can't see anything good in the experience

The selection of these three different categories of people was strategically intended to reduce the possibility of error and bias in the data I would collect (Lofland et al. 2006:93). By seeking to involve as research participants people coming from different positions in relation to the experience of disability, I aimed to avoid repetition of the same sorts of perspectives. Where validity is a euphemism for 'the truth' (Rodriguez and Ryave, 2002:22), I considered it likely I would capture a more valid picture of the experience of disability with a broader range of outlooks. It would have been very easy to argue in support of the affirmative model if all the disabled people I interviewed were upbeat about their personal

experiences and life situations. Developing a critical analysis, on the other hand, would have proved more difficult.

I gave a brief outline of what would be asked of participants, stating that they would be asked to take part in interviews in a series of different situations reflecting different parts of their lives. Interviews, I stated, would be fairly informal, organised loosely around the themes 'Who am I?' and 'How do I fit in to the world?' (Giddens, 2003). I indicated that the social model of disability would be the underlying principle on which the research would be based and that interviews would take place between October 2007 and October 2008. I gave assurance of full confidentiality and confirmed that this project had ethical approval from Queen Margaret University.

I invited anyone interested in finding out more about this research, either because they wanted to become involved or because they would like to pass on information to someone else, to contact me.

On the morning of the day of publication of my letter I received my first enquiries. These proceeded to arrive very rapidly over the coming days. Some people responded directly as a result of having read my letter on the Inclusion Scotland website, but what also surprised me was that the letter appeared to have been picked up and copied into their own newsletters by people working in other organisations. I had originally developed a list of some thirty organisations I planned to target with this letter but it quickly became apparent that this would be unnecessary. While I had initially hoped to receive a handful of responses from disabled people around Scotland who had seen my notice through the Inclusion Scotland website, I received enquiries from people from throughout Scotland, England and Wales. The furthest I received an enquiry from was from a professor at the Georgia Institute in Atlanta, Georgia, who offered to invite the 900 disabled members of their Research Center's Community Advisory Network to participate in my research. (I had to email her back, thanking her for the interest, but stating that regrettably my research budget would not stretch to intercontinental travel.)

I had anticipated a possible difficulty identifying participants who felt negatively about the disability experience. I foresaw that perhaps it might be relatively easy to attract people with positive identities, but that those who found nothing good in living with impairment might be reluctant to talk about their situations. In preparation for this I had developed knowledge about snowball research strategies for accessing hidden and 'hard-to-reach' (or marginalised)

populations (Atkinson and Flint, 2001). Atkinson and Flint have defined snowball sampling as a technique for finding research subjects involving:

one subject (who) gives the researcher the name of another subject, who in turn provides the name of a third, and so on (Atkinson and Flint, 2001:unpaged).

It was my intention, had it proved hard to contact disabled people who regarded impairment negatively, to involve other participants in identifying these, asking if they knew of people who might be approached directly or indirectly in relation to this. There turned out to be no need as I received responses from people in all three of the identified categories. I received an offer of assistance in this matter from a disabled worker in one of the large national charities who said they would be happy to approach their own disabled members. Accessing people from the last group was, I am sure, helped by people unknown to me who distributed my letter through their own organisations. This meant that my letter was seen by people who would never go near the website of a political campaigning organisation, but who had contact with impairment-specific charities.

By the time my letter had been in the public domain for a fortnight I had received 72 enquiries (by email and telephone) from people interested in becoming research participants. This meant I was faced with a problem very different – and far preferable – to the one I had anticipated. My problem now became one of narrowing down the potential list. In order to do this I asked people to get back in touch, sending a short pen picture. Some people had already given me brief details about themselves in their initial contacts, which I found gave me a clearer basis upon which to make a decision. Most people got back to me with pen pictures. Those who had not responded by the end of August I did not include for further consideration. I made the judgement that if I had people from all three positions with whom communication was going to be relatively straightforward there was little point in chasing up people with whom it was not.

I established four categories of people in terms of responses and information I had been given:

- Really positive
- Just getting on with it
- Identify negatively
- A bit of all three

I included this last category because it became clear my initial divisions had been very arbitrary and the information I received suggested it was fairly usual for people to shift between feeling positive and negative about themselves in terms of disability experience. As John Storey notes:

Just as texts are marked by multiple discourses, so are [individuals]. Subjectivity is not something fixed and unchanging, it is always on the move, constantly being addressed by, and always taking up, a range of different subject positions (Storey, 2003:69).

I need to add that my reasons for selecting some rather than others were not because the ones I selected seemed better or to have more that was interesting or valuable to say about themselves than those I did not. My aim was, rather, to gather what seemed to me to be as diverse a range of voices on the subject as possible. In making decisions on who I would invite to participate I had to rely, principally, on my own instinct and feel for the area (Esterberg, 2002). I have included in Appendix B extracts from a number of examples of the types of responses I received. As will be the case throughout my thesis, unless people have asked that I use their real names, all personal names are disguised.

By early September I had narrowed down my choices to twelve people, including Charles and Lola (with whom I had carried out first interviews in August while they were in Edinburgh for the Fringe Festival). These twelve were: Charles and Lola (from the field of disability arts); Ben and Roshni (categorised as *identifying positively as disabled*); Anne, Hazel, Sukhbir and Jennie (categorised as *just getting on with it*); Rose and Kevin (categorised as *identifying negatively*); and Helen and Ash (categorised as *a bit of all three*). I do not claim that these twelve were chosen scientifically or in a way that reflected more than approximately the quantitative spread of responses.

I had to work intuitively with a sense of what I was looking for, hoping that insight would emerge from the people I had chosen to interview. It could be argued that, while undoubtedly different in terms of specifics from the data I produced, it would likely have been the case that I would have emerged with data as interesting had I selected a different twelve people. As it was, two people I invited to become participants did not respond to my further emails and so two of the people I actually interviewed were originally second choices. I do not, however, think the data I might have produced with the people who did not respond would have been any better or that the data produced is any less valuable. What is important is the generalisability of my research, or the question of whether my findings have relevance in

terms of other groups of individuals beyond the specific group of individuals I worked with (Blaxter, Hughes and Tight, 1998). I would contend that, having asked potential participants to identify themselves within certain categories, what was important was to ensure representation from each category. Having interviewed Charles and Lola I contacted the remaining ten people and arranged interview dates with each of them between September and November 2007.

Later on within the research process I added another five different participants for a number of reasons.

Sukhbir failed to turn up for our first arranged interview in Birmingham in November 2007 and, over the course of a further series of emails identified himself as not particularly interested in participating. As I wanted to ensure the inclusion of a BME perspective within the range of accounts I was gathering, I invited Surinder, a disabled Asian woman I was introduced to by Roshni.

The arbitrariness of the initial categories I had identified became even more apparent during my first series of interviews. Some of those initially identified as positive were in some aspects of their descriptions more negative than those who had identified themselves as negative. Some of those identified as 'just getting on with it' were similarly negative. In some areas this worked the other way round, too, so that those who had initially identified as negative were in areas of their discussions more positive about their experience than those who had said otherwise; but overall it became apparent that a sense of negativity was fairly general. Ironically, I was to end up snowballing in order to restore the balance of responses in terms of positive input. Charles suggested I contact Mary and Lola suggested I contact Brian as people who might have interesting input to make in this context.

It also became clear during the first series of interviews that I was talking with more middle-aged than young disabled people. While I had not included age as a criterion for selection, I discovered a bias in terms of the accounts I was collecting towards people in their forties and fifties. As I transcribed these interviews I found myself wondering whether the same sorts of views would be expressed by younger disabled people. I therefore invited Ali and Sarah to participate. Both were in their early twenties at the time of the interviews. Ali is the son of a friend of my wife's who, during a visit, had been talking about the difficult time her son was going through in terms of self-acceptance since his recent diagnosis as having dyslexia. I asked my wife's friend if she would approach her son about this. Sarah is a disabled student at Queen Margaret University.

Robert Stebbins states that for exploratory analytic research, where respondents are interviewed on several occasions, the labour-intensity involved makes a small number of participants appropriate:

I am unaware of any recommended minimum sample size for this sort of exploration, although I do frequently encounter studies based on 10 or 12 cases (Stebbins, 2001:28).

I have worked with sixteen participants. While I am aware that increasing this number has involved perhaps more work than necessary (particularly in terms of transcription), I feel the additional voices have added depth and richness to my data.

Research participants

The people I interviewed included:

Ali, a man in his early-twenties from Whitley Bay. Ali is from a mixed-race English-Iranian background and had recently been diagnosed as having dyslexia.

Anne, a deaf woman in her mid-forties living in Glasgow. Anne has experienced some hearing loss since childhood and became deaf aged twenty-two.

Ash, a man in his mid-forties from a former mining village in Midlothian. Ash lives with depression and has a number of physical impairments sustained in a suicide attempt made in his early-twenties.

Ben, a man in his early-fifties from Coventry. Ben describes himself as having the label of autism.

Brian, a man in his early-fifties living in Brighton. Brian describes himself as having schizophrenia.

Charles, a man in his early-thirties living in Liverpool. Charles has cerebral palsy and is a wheelchair-user.

Hazel, a woman in her mid-forties from Northampton. Hazel has a progressive respiratory condition.

Helen, a woman in her late-twenties living in Edinburgh. Helen describes herself as having been diagnosed as having a personality disorder.

Jennie, a woman in her mid-thirties living in Glasgow. Jennie has a number of physical impairments and is a member of the LGBT community.

Kevin, a man in his early-fifties living near Fraserburgh in Aberdeenshire. Kevin has damage to his brain caused by an aneurysm as well as respiratory impairments and a leg damaged in a motorcycle accident in his twenties.

Lola, a woman in her late-forties from London. Lola has arthritis and is a wheelchair-user.

Mary, a woman in her early-fifties living in Edinburgh. Mary has a visual impairment.

Rose, a woman in her early-fifties living in the highlands. Rose has limb-girdle muscular dystrophy and is a wheelchair-user.

Roshni, a woman in her mid-twenties living in Glasgow. Roshni is blind and is a white revert Muslim.

Sarah, a woman in her early-twenties from Edinburgh. Sarah has cerebral palsy and is a wheelchair-user.

Surinder, a woman in her late-thirties living in Glasgow. Surinder has multiple sclerosis and is a wheelchair-user.

While I have described people's impairments this is not to satisfy a medically-oriented fascination with 'what is wrong' with people, but to illustrate the diverse nature of impairments of the people who participated in my research. While much work in Disability Studies has downplayed the significance of impairment, focusing instead on structural barriers, the affirmative approach I am developing identifies impairment as difference to be expected and respected, not as a characteristic of life to be hidden or considered a source of stigma. While impairments may be diverse, experiences of disabling oppression are patterned along familiar lines.

In the list above I have described some people as being 'from' a place and others as 'living in' a place. Those described as 'from' are still living more or less in the area they grew up in, while those described as 'living in' have moved in recent years. An interesting aspect of having interviewed disabled people across such a wide geographical area is the frequency of parallels in accounts of experiences. While disability is typically represented and experienced as an individual problem, a wider picture can reveal the structural nature of disabling social relations.

I have described participants' ages in order to indicate the age range covered by the people involved in my research. Given a difference of around thirty years between the ages of the oldest and youngest participants, particularly when it is considered that this covers a period where significant changes have been made in terms of life opportunities for disabled people, I have found the similarity of perspectives revealing. I talk about this at greater length during my discussion on disability as role.

The interview guide

Following the outline given in Lofland *et al.* (2006:104) I developed an interview guide to ensure that a number of key ethical issues (e.g. informed consent, confidentiality, ownership and accountability) were discussed and clarified between myself and participants prior to the commencement of their involvement in my research. Before the start of each first interview I went through the interview guide step-by-step, outlining and clarifying each point to ensure that participants were aware of what they were committing themselves to. I obtained each participant's signature as authorisation to go ahead in recording our discussions and using these as data for my research.

I have included a copy of my interview guide as Appendix C.

Three stages of data collection

In order to explore my question from a range of perspectives, I triangulated my research by adopting three different research strategies. As Kristin Esterberg points out

...in-depth interviews can provide insight into people's thoughts and feelings, but people's behaviours don't always match their words. Analyses of texts can tell you about social ideals for behaviour, but the texts can't tell you how people actually respond to them (Esterberg, 2002:36).

I wanted to learn about not only what people feel about being disabled, and about ways in which they have come to think about and make sense of disability, but to see what I could discover about their responses to everyday experiences in a disabling society. I wanted to record not only considered discussion about their personal histories and about media representations of disability, but to try and capture their immediate reactions to experiences of being subjected to disabling barriers.

The three different research strategies involved two in-depth interviews, one semi-structured and one unstructured, and a form of participant observation, or Go-Along research

(Kusenbach, 2003) in which I accompanied participants as they went about everyday activities.

First interviews

The aim of the first series of interviews, carried out as semi-structured interviews, involved uncovering participants' thoughts about their relationships with disability as an idea or an identity. The interviews were developed as guided conversations in which I asked participants to talk about their experiences in terms of where and how they had learned about the meaning of disability, as well as about whether or how their perceptions about disability had changed over the years, and about how they currently felt about themselves as disabled people. I had a number of questions to guide the interviews, though I was flexible about when or whether I asked these in every interview. Participants sometimes anticipated the next questions in their discussion of a topic and so I skipped over these later on. The purpose of the questions was to ensure the themes I wanted to explore were covered within each interview, but it was left very much down to each participant to go where they wanted in making reply. I worded my questions as 'tell me' questions in order to leave the way open for participants to respond in terms of their own experiences and categories (Lofland *et al*, 2006).

My own role involved listening carefully to the participants' responses and following the leads they gave, questioning and probing further in response to where they took me, but being able to return, if and when appropriate, to the next question when the participant felt they had said all they wanted to say relating to particular area of discussion (Lofland *et al*, 2006).

Questions used in my first series of interviews

1. Please tell me about when you became aware of the idea of disability; of a distinction between disabled and non-disabled people; of where you situated yourself in relation to these groups; and about how you felt about each group.
2. Tell me about when you first began to think that you might have an impairment; whether this was something you worked out for yourself, or whether this was something you became aware of because of the way that other people talked and behaved towards you; and about how this made you feel.
3. Tell me about when you first accepted the idea that you were a disabled person and about how this made you feel.

4. Tell me about the people who were around you when you discovered you had an impairment; about whether you were able to talk with people about how you felt; about whether you felt okay about talking about it with other people and about whether what they said was helpful or unhelpful.
5. Tell me about any changes, if there have been any, to do with the way you think about yourself as a disabled person; about ways in which your thinking about disability has developed; and about what you think might have caused these changes.
6. Tell me about how you feel towards and relate to other disabled people now.
7. Tell me about any tensions you might feel between your identity as somebody with an impairment and other aspects of your identity; for instance in terms of being a family member or in terms of gender, sexuality, ethnicity or faith.
8. Tell me about how you feel about yourself, as a person, and about whether you're happy or unhappy being who you are.

In asking these questions I was seeking to uncover something about participants' structural positions and about their own experiences. This involved respecting situations where people have successfully accommodated themselves to various structural features of their lives, but recognizing also the essentially exploitative nature of these structures (Finch, 1984:84). I wanted to move beyond what Vic Finkelstein has identified as the choice between an 'outside in' or an 'inside out' approach – concentrating either on the barriers 'out there' or on disabled people's subjective reality – and to attempt to relate these aspects of experience (Barnes and Mercer, 1997:7). I would argue that much division within Disability Studies is the result of a perception that this is an either/or matter.

During the first two interviews I carried out, with Charles and Lola in August 2007, I did not place time limits on interviews. The interview with Charles lasted one hour fifty minutes and Lola's lasted two hours ten minutes. I decided, following this, that I should place an absolute limit of two hours. This was a practical resolve made as I discovered how long interview transcription takes. As it turned out, most interviews took around 90 minutes to complete, with some slightly shorter and some slightly longer. Interviews took place in participants' homes, at workplaces, at Queen Margaret University and at a university in Birmingham. I made observational notes and memos following each interview while the memory of what had taken place was still fresh in my mind.

In common with Janet Finch, who has discussed the ethics and politics of interviewing women (1984:70ff.) I was initially somewhat surprised at the readiness of participants to talk

to me. I had expected interviewing to involve some sort of formal exchange in which I would have to work to establish rapport, but the experience was more like having a friendly chat. Drawing on Finch's description and applying this to my situation as a disabled person interviewing disabled people (women and men) I would suggest there are a number of reasons which made this such an uncomplicated process.

It seems to me that there are grounds for expecting that where a woman researcher is interviewing other women, this is a situation with special characteristics conducive to the flow of information (Finch, 1983:74).

It became clear that many of my participants found the interviews a welcome experience in contrast with the lack of opportunities to talk about themselves in other circumstances. I was told a number of times at the start of second interviews that talking in the first had 'helped', an outcome I had not foreseen. One theme emerging from the first series of interviews is the sense of isolation experienced by many disabled people as they have tried to make sense of their lives. Reflecting upon relationships and events while being listened to by another disabled person in the interview context may have enabled participants to organise their feelings about being disabled.

Second interviews

The second series I carried out as unstructured interviews. Apart from a general opening invitation to participants to tell me about their perceptions of media representations of disability as resources to draw on in making sense of their own experience, I had no prepared questions. One of my aims in this involved enquiring whether what is perceived as an increased number of representations of disabled people in mainstream media necessarily signifies an improvement in what is represented. I hoped also to explore the extent to which participants felt their perceptions of disability were shaped by popular culture.

Following Janice Radway, I wished to avoid beginning with a particular text or series of texts and then seeking to demonstrate how these texts are consumed. The trouble with such an approach would have been to make the assumption that the research participants 'are already stitched into a particular kind of relation with the [text in question]' (Storey, 2003:68). I hoped that participants would tell me what they considered important rather than that I should presume to decide this beforehand.

As Kisten Esterberg notes, of all interview types, unstructured interviews tend to be the most like 'real' conversations (Esterberg, 2002:89). Essentially, that is what these were: recorded

conversations. The fact that I felt able to carry out unstructured interviews perhaps also reflected growing confidence in my ability as an interviewer. These interviews were carried out between January and June 2008. Interviews took place in a variety of settings: in homes, at workplaces, at Queen Margaret University and at Coventry University Students Union.

Third interviews

The third series involved observations as participants carried out a variety of everyday activities. I also carried out short unstructured interviews before and after these activities, asking participants to tell me about what they anticipated in an event and, afterwards, how they felt about what had occurred. In this I wanted to explore tensions experienced by participants as they were experienced and before there had passed any time for real reflection.

I took a slight risk with this as a strategy, for it might have been the case that no tensions were experienced during the course of what followed. It could have turned out to be the case that during these observations there was nothing encountered to give participants cause for angst. Everything might fall into place in terms of access and impairment might have been regarded by all met with as an ordinary part of human life. The point, however, was not actively to go out looking for tensions where none existed, but to consider these as they might typically be experienced.

I aimed to look at everyday life situations, at the private narratives and the sorts of stories disabled people tell themselves as they go about their routine business. Through this I hoped to challenge the validity of the personal tragedy model of disability and its underlying assumptions, for example:

- that any work or pursuit we undertake, is done so as ‘therapy’ with the sole intention of taking our mind off our condition
- that we don’t have any real or significant experiences in the way that non-disabled people do
- that we are naïve and live sheltered lives
- that we desire to emulate and achieve normal behaviour and appearance in all things

- that we go about the daily necessities or pursue an interest because it is a ‘challenge’ through which we can ‘prove’ ourselves capable

(Morris, J. 1993:19)

By exploring a range of very different everyday experiences with disabled people I aimed to question these sorts of assumptions by asking, for example:

do such assumptions really describe disabled people as we are or do disabled people tend to just get on with life and do the things we have to do or want to do as a matter of course?

when disabled people are ‘in the thick of it’, are they thinking about being disabled or are they just thinking about what they are doing?

are they conscious of both being and doing at the same time?

how do disabled people feel about themselves as disabled people while they are getting on with things, or is awareness of disability only recalled when somebody points this out or makes an unhelpful remark?

I intended also to address the medical and social models of disability (when people with impairments do encounter problems in their everyday lives are these to do with who they are as individuals or are they to do with physical barriers and other people’s attitudes), as well as to explore the usefulness of a clarified affirmative model.

Following discussion with each participant, agreement was reached on a number of very different everyday situations to consider:

- celebrating a 50th birthday
- visiting an online chat room
- going for a meal out with a friend

- going out for a coffee with a partner
- spending an afternoon volunteering in an office
- spending a morning running a self-advocacy group
- spending a morning working at home
- going for a train at a major city railway station at rush hour
- cooking an evening meal
- going shopping
- watching an episode of *Deal Or No Deal*

In some cases I observed different people carrying out the same activity in different settings. For example, I went shopping with three participants. I watched the same episode of the Channel 4 game show *Deal Or No Deal* with four participants (I had obtained a DVD of the show from Channel 4).

I adopted a fairly flexible approach to identifying ‘everyday situations’. Quite obviously disabled people do not routinely celebrate 50th birthdays on an everyday basis any more than anybody else does. My primary concern was that participants should do things they felt comfortable about and would ordinarily have been doing anyway.

Following Up

Following each interview I transcribed the recordings and emailed the transcriptions to participants for confirmation. I told participants to feel free to add to or amend any parts of the transcript they wished, but to let me know if there had been any changes when returning these.

Participants returned the scripts requesting very few minor changes relating, for example, to the spelling of a medical condition, the use of a friend's name which someone wanted changed, and a request to remove something somebody had quoted their father as saying.

In summer 2008 I received a very kind offer from a friend, Eleanor Coner, who I had been talking with about my research and the trials of transcription on a train journey back from Edinburgh to Dunbar. She offered to assist with the transcription of interviews, an offer I eagerly took her up on. While I don't think she quite anticipated the volume of work she was getting herself into, she has helped me greatly by transcribing around twenty of the total forty-eight interviews I carried out during the course of my research. I gained assurance from Eleanor about the necessity for confidentiality and that these interviews should not be discussed with anybody. She has refused to take any payment for her help.

Open coding

During and after interview transcription I began a process of open coding, working through the scripts line by line to identify themes that seemed of interest in relation to my research question. I did this by using highlighter pens to highlight themes and making notes and short descriptions in the margins beside text. Initially themes seemed to range over a wide area, but the further I got into the process the clearer it became that certain themes recurred more frequently than others in discussion not only with each participant but also between participants. I did not pre-define codes or themes but let them emerge from participants' comments and reflections (Lofland *et al*, 2006).

I carried out open coding procedures with all interviews, making lists of my codes by hand, in ink, in a large book I had bought for the purpose.

Focussed coding

This process led to the emergence of frequently recurring themes, categories raised and discussed by several participants during interviews. I then considered which of these would be most useful in developing my analysis.

I revisited my interview transcripts, copying highlighted passages relating to a particular theme and pasting in a Word document alongside other participants' comments on the same theme, along with names and line numbers so that they could be re-identified easily. I then went over these collected passages thoroughly a number of times, identifying areas where

aspects of themes overlapped so that they could be classified under one larger general category (Lofland *et al*, 2006).

For example, in relation to the first series of interviews, after open coding I initially emerged with 42 themes (listed in Appendix D). I read through the passages again and again, identifying areas of similarity and thematic overlap, narrowing them down into eleven refined themes (see also Appendix D). I then repeated this process until I emerged with five master themes for analysis:

Distance

Intrusion

Bodies

Closeness

Power

Memos

I have been making memos almost continuously since carrying out the interviews. As Kristin Esterberg notes, memos can take ‘whatever format you like and feel most comfortable with’ (Esterberg, 2002:165). I have bought 14 spiral-bound notebooks, each with 72 blank pages, which I have filled with notes written in numerous situations: from short notes to myself made during actual interviews; to interview summaries and records of physical spaces immediately following the interview; to copious notes during transcription relating comments made in one interview to similar comments made in others and relating comments to theoretical insights in books I have been reading; to thoughts jotted down that have occurred to me while watching television, reading the newspaper, waiting for trains, during train journeys, cooking tea, walking the dog.

Setting it out

In the following chapters where I have included participants’ statements taken from interview transcriptions, I have identified the location of these in terms of interview and line numbers. After quoting a statement made by Roshni which can be located in the 24th and following lines of her first interview, for example, I identify this in brackets at the end of the quote.

l = line

l: = interview number

24ff. = line numbers within interview 1.

When I was very, very young I never felt that there was anything I couldn't do... I climbed trees, I would go out to play with the other kids, I would cross roads and run in front of cars and do lots of dangerous things like that... but I was never aware of the fact that I couldn't see... (l.1:24ff).

The identity of the speaker is made clear within the text.

I have included my interview transcripts on the c.d. included with my thesis.

Chapter 4: Subject Positioning

Introduction

I have rediscovered a memo I made in September 2007 as I was on my way to a highland town to meet and interview Rose for the first time. Rose has asked that the name of the town she lives in should not be disclosed.

At the railway station, buying tickets to travel for my first interview with Rose, I find Mr McHenry, a wee man with a white moustache, serving.

“Return to the highlands, coming back today,” I say.

“The highlands!” Mr McHenry exclaims. “My, you’re travelling a long way!”

This is the guy who, some time ago, questioned the idea that I could travel to London by myself.

“Are you sure there’s nobody going with you?” he had asked then.

On this occasion I explain to him that I’m going to interview someone for my PhD.

I suppose that’s about trying to assert my identity as someone who’s competent and has a right to travel on my own to the highlands if I want.

“And how long’s your PhD going to take?” he asks.

“A couple more years...”

I’m not sure whether he believes me or whether he’s convinced I’m living in some handicapped fantasy world.

Probably the latter.

Interactions such as this can really piss you off, put you out of good humour, leave you going over the situation again and again.

Why did I feel the need to state the purpose of my journey? Because I wanted to let him know that he’s mistaken in his judgement about me. But why should I have to justify myself?

I'm being pushed into a subject position that I'm not happy with. I am being disabled by him. I sense that he is fixing me with a gaze of... pity, I suppose... this is not something I want.

Some discourses, and the subject positions and modes of subjectivity and identity that they constitute, have more power than others (Weedon, 2004:18).

This is a man who performs mechanical tasks, selling tickets, providing information, waving trains in and out of the station... repetitive tasks, day in, day out... and yet... he occupies a subject position as a non-disabled person.

In this chapter I draw on participants' accounts of their own experiences to explore their subject positioning within conflicting disability discourses. I do this in order to develop an understanding of what being disabled means for disabled people and to begin to consider reasons given for accepting or rejecting disability identity. I conclude by offering revised affirmative model definitions.

Discussion of themes raised in my first series of interviews will cover this and the following chapter. These themes are not dealt with equally in terms of length but in terms of their relevance to the development of my thesis. For example, my discussion of the theme of Distance takes up the whole of this chapter. The names I have given themes are intended as rough indicators of thematic detail rather than as precise descriptions. Each covers a wide range of issues talked about by participants. I have also divided my thematic discussions into sub-headed sections order to make them easier to follow.

Distance

I use the concept of distance to refer not only to the actual physical distance that frequently separates the lives of disabled and non-disabled people, but also to the emotional distance that is an outcome of that separation.

Describing her early childhood experience as a blind girl living in East Kilbride, Roshni remembers clearly her sense of being included by her playmates as just 'one of the gang':

When I was very, very young I never felt that there was anything I couldn't do... I climbed trees, I would go out to play with the other kids, I would cross roads and run in front of cars and do lots of dangerous things like that... but I was never aware of the fact that I couldn't see... (l.1:24ff.)

Her impairment seems not to have been a hindrance to participation or acceptance. While she later describes encounters involving:

kids who would come up to you and go “Oh, what’s wrong with your eyes?” kind of thing, and “Can you see how many fingers I’m holding up?”, you know... (l.1.70ff.)

this was in the context of being included within local children’s play. A perception of difference as inferiority appears not to have existed. This idea is supported in a comment made by Jennie, describing her own friendship with a girl who had Down’s Syndrome:

I had come across that as a concept that other people could have that would cause them problems in similar ways... but it was... you know, a problem that she had like other people might have a problem with... say... being overweight, or not being very good at maths, or whatever it was... (l.1.79ff.)

Impairment was perceived as something that might cause problems for the person concerned, but was not considered a tragic circumstance that gave reason for avoidance.

Where, occasionally, disabled adults were seen this was not something a great deal of thought was given to. Anne recalls:

walking around Glasgow with my parents for whatever reason... and we would see someone begging who only had one leg... but you don’t think of them as a disabled person... you don’t question it... it’s just part of the scenery... you’re more excited about getting a bag of sweets than what’s going on around you... (l.1:17ff).

Such accounts paint a picture of children too pre-occupied with the fantastic business of being alive to be conscious of silly things like personal limitations. Physical difference does not appear to have been considered significant until the onset of segregation, when suddenly children with impairments found themselves separated from the other children they knew. Lola describes a sense of difference that began to emerge at a very young age as a result of being sent to attend a special school at a considerable distance from her home:

I can very clearly remember... erm... being very puzzled by this... that my school was going to be twenty miles away from where I lived...I would be picked up in a special bus... and I wouldn’t go to school with my brother... I wouldn’t be picked up by my mum... so, of course, this awareness of difference and separation began at that time... (l.1.23ff.)

The emergence of a sense of difference and separation is echoed by Sarah, who describes a growing sense of distance from other children in the Leith community where she lived:

the school was, like, an hour away from my house and so I would go away from the people I was around all the time, and I would go to this school... and then I... you know, I'd be there from nine in the morning till three in the afternoon... and I... then you'd be sent home and you just wouldn't mix with the same people you spent your time at school with... and that's when I started to notice that my life was different cos obviously, I didn't go to the school with the people in my community... which was a bit strange... (l.1.34ff.)

This perception of things being 'a bit strange' is further compounded by Sarah's remark that:

you're made to do physio and things like that.... and you're told that this is something you have to do... but, yet... I don't think it's really... it's not explained to you... really, at that age... you just kind of have to, like, deal with it... (l.1.21ff.)

There is no explanation given. Children have been uprooted from their communities and their friends to attend distant schools where they are 'made to do physio and things like that' but are left for themselves to make sense of what is happening to them and why they no longer spend their days with their brothers and sisters and friends from the street. Significantly, no explanation is given that makes any reference to concepts such as 'disability' or 'handicap'. Mary remarks of her time at a London special school that:

I went there from when I was six to... nearly fourteen... and I left... without, I think, the words disability, handicap... certainly not impairment... ever being mentioned... (l.1.133ff.)

There is something paradoxical about the practice of removing children with impairments from other children, failing to tell them why, and then exhorting them to 'be like other children'. The other children from whom they have been distanced, both physically and emotionally, have by this time become alien beings. Just as it has been observed that many non-disabled people's only knowledge of disabled people is based on what they see in the media (Rieser, 2002), so the reverse seems to have been true in Charles' case. As a residential pupil at a special school in Newcastle upon Tyne, his only knowledge of non-disabled children was based on what he saw on TV during the 1980s:

Grange Hill used to scare the willies out of me... Grange Hill compared to my special school... Grange Hill was like... a war zone... (laughs)... do you know what I mean... just seemed like a completely different world... (1.1.26ff.)

Speaking as someone who attended a mainstream school, whose impairment had not yet been identified, Helen remarks of growing up in the highlands:

About five miles from my village there's a town which has a special school... if you went oh, and this person went to St Mark's... everyone knew what that meant... I guess the thing was cos it was separate, you didn't end up mixing with the kids who went there, especially as you got older, because... depending on the type of problems they had, they tended to be learning difficulties and stuff, you might not have a sort of peer group interest in stuff... (1.1.160ff.)

For those attending mainstream school, disability is regarded as not their problem and as having nothing to do with them. As Keith Ballard and Trevor McDonald suggest, being disabled is:

to be at risk of labelling that can exclude you from learning opportunities and segregate you from your friends and community. To be segregated can mean that you are treated as less than human (Ballard and McDonald, 1999:112).

Mary describes the steady erosion of contact with the children she had formerly played with, the result of the fact that she now saw them rarely and recognised that she had little in common with them:

Gradually the relationships I had with children who lived in the neighbourhood became less and less... and by the time I got to about... ten or eleven... erm... in summer holidays I didn't really play outside at all... didn't go out and play with anybody... (1.1.224ff.)

Absence of friendship

If it is assumed that children removed in this way will naturally and easily form friendships with 'others of their kind' at special school, participants suggest otherwise. Speaking about the London special school she attended, Lola recalls that:

I saw the other disabled kids and knew that I was now identified with them...and yet I didn't feel that I belonged to them... was I disabled, or was I normal... you know... I would push kids around in their chairs and do things for them because, although I had a lot of pain and I had a lot of issues around stamina, and I was often ill, I was fully mobile... (l.1.30ff.)

The range and levels of impairments in special schools can lead to frustration and resentment about what is and is not expected. Roshni reflects on the lack of opportunities to mix with others she could relate to easily:

when I went to school, obviously I knew that I went to a special school... cos I went to school for the visually impaired for my primary part of my schooling and... so I was aware again of a difference but it was very subtle, because even then I think I saw myself as very different from the other children... because there was nobody even in that environment that I identified with, because a lot of the other children had complex needs... (l.1.123ff.)

Sarah recounts the way in which she was used as an example to others but felt there was nobody for her to identify with:

I started off being able to use cutlery and they put me at a table with people who couldn't eat and stuff... couldn't eat themselves... and what they said to my mum was "Well, we've put Sarah with people who can't eat as well to bring them on..." my argument is, even now, who was there to bring me on... who's there to inspire me... who's there to make me think "I can do that"... (l.1.288ff.)

Friendship is an important aspect of children's emotional development, one which ideally provides space to learn about self through seeing oneself reflected in others, as well as providing a range of opportunities to test out identities. William Corsaro comments that children's social identities are oriented toward alliances with other children (Corsaro, 1997:168). Being situated in a place where one has been removed from what one knows yet does not feel one belongs is an isolating experience for children. When to this is added the fact that little explanation is given for this situation, it makes sense to reason that the growing awareness of personal difference and distance from others is likely to be experienced negatively.

Low expectations

Once you're there you're not expected to do anything particularly, or have any aspiration to anything... (l.1.63f.)

Lola is not alone in remembering how little was expected of children attending special schools. Kevin, who, because he had asthma, was sent at the age of eleven from London to attend a boarding school near Guildford in rural Surrey, recalls that:

their main priority in the school was not education... they deemed that too much education was too stressful for us deli... we were classed as 'delicate boys'... you went into this special school, where they said "No, Kevin... your learning's not very important, we've got to focus on your exercise..." (l.1.105ff.)

That emphasis on exercises was regarded as having priority over learning is echoed by Sarah who describes how, in terms of her own experience thirty years after Kevin, little seemed to have changed:

I wasn't pushed, I was just bored... my mum and dad saw special school as, like, a place to get physio... I mean, I did get lessons, but it wasn't anything challenging... (l.1.254ff.)

Sarah expresses frustration at the mixed messages she received between home and school. While her parents' intentions were that within the family as far as possible she and her older brother would be treated with the same expectations, at special school she received a different message:

You know, my mum and dad would treat me normal... and then I'd go into this school and it was like "Oh no, you don't need to eat with cutlery, we'll give you this special bowl and a special..." ...so it's like you're really confused, and I was really... you know, as a young kid you're wondering "Where am I? Where do I fit in?"... you know, you're telling me one thing and my mum and dad are telling me to be another... (l.1.315ff.)

The fact that little focus appears to have been placed on the formal education of disabled children suggests that little is expected of them beyond school life. Having received little opportunity for academic learning while at school, many young disabled people emerge ill-qualified for employment. In a 2005 report for the Joseph Rowntree Foundation, Tania Burchardt shows that, in spite of sharing the same aspirations as their non-disabled peers for

work and independent living, the chances for disabled young people are considerably less and that inequality of opportunity increases as they get older:

At age 16/17, disabled young people were about twice as likely as non-disabled to be out of work... at age 26, young people who were disabled at both age 16 and 26 were nearly four times as likely to be unemployed or involuntarily out of work than young people who were disabled at neither age (Burchardt, 2005).

Mary expresses a sense of continuing disillusionment at the impact of this experience on the lives of people who have been through the special school system:

When I think of it, and I do think... what a very damaging experience that was for a lot of children... because, on the one hand, we were taken there, told all these things that... you know... you can do all the things that everybody else can do... you know... have all the... there are no differences between you and everything... and then, of course, immediately you came to interact with the world outside this, those differences are apparent... (l.1.149ff.)

Assimilation

A further example of what is being revealed as the often confusing experience of attending special school is encountered in the fact that children were encouraged to emulate the behaviour and appearance of their non-disabled counterparts. Great emphasis was placed on the value of appearance as normal, or as close to normal as possible. Charles remembers that:

I didn't use a wheelchair in school, I used like a walking frame so... I didn't really use one of those at home but at school I'd see like wheelchairs... and you've sort of got... like, you're under pressure to not end up in a wheelchair, to keep walking, yeah, and standing frames and all that... (l.1:62ff.)

The message being conveyed, and repeated throughout the special school experience, is that it is the responsibility of disabled people to do their best to hide their impairment, to distance themselves from impairment. Success depends, above everything, on emulation of non-disabled people and assimilation: appearing more like non-disabled people and less like other disabled people. Hierarchies are created within this segregated environment. Those who manage to keep walking are rewarded with praise for their efforts. The point of walking or 'nearly-walking' is to appear more like the non-disabled. It is to give assent to the assumption of non-disabled superiority.

Mike Oliver, in a discussion of walking and ‘nearly-walking’, points out that:

In terms set by the rehabilitation enterprise, walking is rule-following behaviour. Not walking is rule-ignoring, rule-flouting or even rule-threatening behaviour (Oliver, 1996:104).

The pressure to keep walking described by Charles, involving the use of adaptive aids and equipment, exposes another side to the function of special education. ‘Nearly walking’ involves compliance with the requirements of normality while also involving an acceptance of the inferiority of not-walking. Shame and stigma are attached to not-walking, which in Charles’ situation is represented as ‘giving in’. What is being taught is a rejection of disability as a valid identity.

As Emile Durkheim has put it:

In each one of us, in differing degrees, is contained the person we were yesterday, and indeed, in the nature of things it is even true that our past personae predominate in us, since the present is necessarily insignificant when compared with the long period of the past because of which we have emerged in the form we have today. It is just that we don’t directly feel the influence of these past selves precisely because they are so deeply rooted within us (quoted in Bourdieu, 1990:56).

The rejection of self absorbed within an imposed regime of ‘nearly-walking’ becomes embedded deeply. The disassociation of self from impairment involves a denial of the value of one’s own experience, and is a form of entrapment which can involve disabled people in more or less constant feelings of either frustrated negativity about themselves or passive acceptance of imposed limitations.

Charles speaks later of how, encountering non-disabled young people on a regular basis for the first time, at sixth form college at the age of sixteen, he would downplay the significance of impairment as part of his sense of self:

What I wasn’t used to was people asking me about being disabled, because at special school it wasn’t something that was talked about... and sort of, how do I, like... to start off with you just say (laughs) oh, you know, I just get on with it... (laughs)... that sort of thing... doesn’t really... it’s not really part of my life... (1.1.139ff.)

Mary remembers that:

all the time we were extolled to... erm... to act like other children... to be like other children... I don't know who these mythical other children were, mind you, but that was the kind of culture there... it was a culture that really denied children any sense of themselves as being disabled... (l.1.137ff.)

The emerging picture is one in which disabled children are removed from other children yet told to be like other children; segregated on the basis of being identified as disabled, yet within physical settings where disability is never talked about.

Institutionalisation

When I went to boarding school it was still a segregated environment up to sixteen... and we had these, like, uniforms, orange and green uniforms, and we... you had to wear the uniform obviously five days a week... but if you went into the town on a Saturday you had to wear the uniform to identify you... and, of course, Sunday was church, and you had to wear the uniform for church... so you wore that uniform for seven days a week... erm... not all... I mean, you could take it off in the evening if you weren't going out or whatever, but it's that kind of... (l.1.124ff.)

Charles' statement indicates that the special school environment was one which involved training in disciplinary techniques. The importance of conformity and self-presentation as respectable and compliant is drilled into the young disabled consciousness through the wearing of school uniforms whenever in the public eye. Michel Foucault describes the ways in which becoming a subject involves developing habits of self-control and self-monitoring as if one is at all times being watched and evaluated (Foucault, 1987). Normalising disciplines create the awareness of impairment as 'a deficit of corporeal integrity and – simultaneously – as an invalid social position' (Hughes, 2005:83). As Bourdieu notes:

the anticipations of the habitus... give disproportionate weight to early experience... it ensures the active presence of past experiences, which, deposited in each organism in the forms of schemes of perception, thought and action, tend to guarantee the 'correctness' of practices and their constancy over time, more reliably than all formal rules and explicit norms (Bourdieu, 1990:54).

In discussing social structures as 'patterned regularities that characterise most human interaction' (Stryker, 2002:65), Sheldon Stryker remarks that:

Whatever may be true of the creative potential of persons in their interactions with one another, as a matter of empirical fact most of their interactions tend to be with

the same or only slowly changing casts of others, and the same sets of persons tend to be bound together or linked in interactional networks doing essentially the same things on a repetitive basis (Stryker, 2002:65).

From having earlier described the way in which she did not initially see herself as ‘belonging’ to other disabled children, Lola recalls that this was an identification which developed as she became more disconnected from the friends she had where she lived (l.1.79). At the age of eleven she found herself living in a medical residential unit where she spent most of her time (apart from being allowed to return home occasionally at weekends and at Christmas) until her late teens. She describes the sense of incarceration she experienced as a teenager:

The regime was extremely strict... very institutionalised... I mean, we were in the middle of nowhere in the very wooded countryside...in the Home Counties... I mean... you couldn’t... you couldn’t go out the front gate and walk down to the shop... I mean, it was effectively, like, a prison...because you had no life, at all, outside of it... (l.1.133ff.)

Lola expresses the conflict experienced by many young disabled people in being in a physical space they don’t want to be in, yet at the same time coming to accept that this is ‘for their own good’. She describes the onset of puberty and a growing sense of self as a time of extreme anxiety during which she developed mental health problems:

I went on a real downhill phase, and I think it was partly because... so I was suddenly very conscious of who I was... having hit, say, around thirteen... at fourteen I was having very serious anxiety episodes, I would lock myself in rooms... and, of course, there’s a lot of dilemma and internal conflict with... I still didn’t know whether I would belong to the kids at special school... I didn’t know where I belonged (l.1:291ff.)

She also, however, acknowledges the good intentions of the professionals who ran this regime.

I can see that they actually did want you to ultimately be equipped to go into the world... they didn’t want any of us to fail... it was the opposite of special school... although it was a dreadful institution and it created all kinds of problems of dependency, ironically, this idea that you take three hours to put your own socks on with a fancy gadget, they were very into that... (l.1.639ff.)

The theme is repeated that being independent (or as independent as possible) is normal; being normal is desirable; being able to put your own socks on is what normal people do; even if you have to take three hours to put your socks on you are showing a willingness and a desire to be like normal people; that impairment is not to be accepted, must be struggled with, must be overcome if you want eventually to succeed in the world outside.

Describing the arrival in the unit of Violet, a girl two years older who was to become a great friend, Lola's description of the other girls around her is revealing:

So she was going to art college, it would all be worked out, she'd find a way... and that was very powerful to see when you've got, basically, rows of other kids your age, obeying the system, you know, like nodding dogs in cars, just going yes, yes, yes, yes... and doing their Buttons and Bows, and whatever... and then Violet saying that if she couldn't find a way to put her own socks on, then she'd ask the milkman... (laughs...) (l.1.932ff.).

Segregated education and institutionalisation has a long-term effect upon confidence and ability to form ordinary relationships. Kevin remembers that:

When I left school I also found that hard, as well... as a result... oh God, it was hard... so, you know, it doesn't just stop at sixteen... the after-effects... there was also the added fact that I was a school boy and I was mixing with grown-ups... and I wasn't used to mixing with grown-ups... and they all used to say to me, they said "You don't talk much, do you?" ...but I never... I used to think all the time... about what could I say to them... I just didn't know what to say... you know, I just hardly said a word all during my training courses... because we were unsupervised the growing-up process never really took place... and I think I was still a child... yes... mentally... although I didn't act like a child... I never really grew up, I don't think... (l.1.527ff.)

There are fundamental contradictions involved in the removal of children identified as having impairments from the mainstream with the stated purpose of fitting them for the mainstream. Kevin's comments reveal the effects of emotional deprivation and the loss of opportunities for ordinary life events and social interactions when placed in settings outwith the family. Mike Oliver has denounced such practices, saying:

If able-bodied children were taken from their local school... (and) forced to undertake physical exercise for all their waking hours to the neglect of their academic education and social development, we would regard it as unacceptable and the children concerned would rapidly come to the attention of the child-protection mafia. But in the lives of disabled children (and adults too), anything goes as long as you call it therapeutic (Oliver, 1996:107).

What is sometimes perceived as the immaturity or vulnerability of disabled people is not an outcome of impairment, but the outcome of being situated within segregated social environments.

From the other direction

The segregation of disabled people from the social mainstream means that, until relatively recently, many non-disabled people have had little familiarity with impairment and, when confronted by it, have found it strange and frightening. Hazel, Rose, Ben, Helen, Ali and Surinder are people whose impairments only became apparent or received diagnosis in adolescence or adult life. Growing up they attended mainstream schools and did not consider disability an issue that affected them. Hazel talks about her first recollection of meeting a disabled person in Northampton at around the age of fourteen:

a friend of the family had a grand-daughter who used to attend a special hospital about three miles from where I lived... and my mum and dad said one day would you like to go and see Spencer's grand-daughter... and I said I would, and she had, erm... multiple disabilities, really, and she was in a room with people with lots of different disabilities... and that was my first experience of... going into a room and actually seeing people who had different disabilities... which at the time, I must admit, I found distressing because I was only a teenager myself... (1.1.18)

While the large institutions where many disabled people were expected to see out their days have now mostly been closed in Britain, the experience of having grown up in a social world where few disabled people were seen still shapes the beliefs and expectations held about impairment by many non-disabled people today. When impairment has been understood as best hidden away, as it literally has been, and relegated to the margins of society where it is identified as a medical and 'care' issue, regarding the possibility of becoming impaired as anything other than negative is very difficult.

Hazel struggled to recall any other disabled people she had encountered during her childhood but eventually remembered:

two sisters that lived, I suppose, about half a mile away from me, and they were adults when I was a child... who, I suppose, looking back, yes, they did have a disability, because I can visualise in my mind that they used to walk along the road chuntering... and they walked with a limp... and they were obviously living with a disability in the area... but I didn't know them particularly... and no, actually, I wasn't aware of people living with a disability round my area... (l.1:96ff.)

Similarly, Rose had difficulty remembering any disabled people in the Derbyshire town where she grew up other than:

a little boy... well, a big boy... who was referred to by my mother as a mongal... who was wheeled around the town we lived in... in a push chair... and who used to be parked outside the chemist occasionally when I had to go on errands for my mother... and he was just left there... and we were told not to talk to him... so, in fact, that was my earliest experience of disability... but I didn't really think about it... he was just an oddity... (l.1.53ff.)

While these accounts suggest that some people with impairments were, in fact, present within ordinary community life, it seems they were rarely seen and were encountered as freaks. The two sisters and the boy with learning difficulties are remembered because it was unusual to see disabled people at all. Rose suggests that:

I think that one of the reasons my mother said that we weren't to talk to the mongal boy was fear on her part... but also... almost a fear of contamination... you know, I had a sense of... something might happen to us if we talked to him... (l.1.99)

Birmingham-raised Surinder also talks about a fear of contamination, citing this as a reason why people with impairments and long-term conditions are often avoided within Asian communities (l.1:98ff.) She speaks of her first recollection of seeing a disabled person, at the age of nine during a family visit to the Punjab:

I think it was, like, quite surprising and shocking, because I wasn't expecting it and I didn't know it because in my environment, in my world at the age of nine everybody was okay ... everybody was perfect, everybody was ... erm ... I didn't see people with disabilities... they weren't ... they definitely weren't seen... erm... because in the Asian culture ...erm .. it's a shameful thing, it's a thing that you wouldn't

display... you stay indoors and you don't show such a shameful thing.... (1.58ff.)

Surinder states that this stigmatisation arises within Asian communities not just from fears about health but from strongly-held religious beliefs:

it's something... erm ... which you could link to past lives and maybe have done something which is very sinful and therefore you're being punished in this life for ... erm ... what you've done in the past (1.75ff.).

The negativity about disabled people conveyed by parents and communities was presumably taken on board and learned as a natural and appropriate response. Impairment was something to be feared, ignored, hidden or turned away from.

Disability was about other people, not about us

Growing up in family situations where the presence of disability was denied was a feature of Ben and Helen's accounts. Describing his Coventry upbringing, Ben talks about the way his grandfather was never considered disabled in spite of the fact that he had severe bronchitis and mobility restrictions:

What I didn't really recognize, really, was the disability in my family... my grandfather never went out... and I was used to the apparatus of disability around... whenever I visited my grandparents... the apparatus around him, the oxygen bottle in the corner, the commode downstairs... and knowing that he had to be helped upstairs... and that he never went out in his older days.... I didn't associate that with disability, that was just sort of normality for my grandparents... and I don't think... I just related to my granddad as an ordinary person... and, I later learnt actually, though, from my mum, when my mum first started using a wheelchair, that he was ashamed to go out in a wheelchair... (1.1.25ff.)

Ben's grandfather preferred the isolation and limitation of activities resulting from self-imposed confinement within his own home to the shame of being seen by others outside in his wheelchair. He would rather appear relatively independent within his own home than suffer the ignominy of appearing disabled in others' eyes.

Helen tells of how her mother, a General Practitioner in the highlands, has gone to lengths to keep her own mental health problem a secret even from those closest to her:

I thought my mum's depression was a fairly well-known fact... but we went down

to one of my aunties' for a party and all the rest of the family were there... and my mum forgot to, like, bring some medication... and my aunty's also a GP so she, like, wrote my mum a prescription... and I realised my other aunty and uncle had no idea my mum was still on anti-depressants and medication... cos my mum was making a real effort to hide why she needed the prescription... even though my other aunty clearly had to know... and I was like "Oh! she doesn't even... and that's her sister..." ...you know, and I think cos my mum's got a thing about it... and it doesn't make sense, because their father was bipolar... and I don't know why my mum should be almost ashamed of this, but you know, she obviously kind of is... (l.1.939ff.)

A sense emerges from these statements that disability is often considered to be about 'other people' but never about 'me' or 'us'. It is perhaps easy to understand the strenuous efforts made by Ben's grandfather and Helen's mother to distance themselves from being identified as disabled, both in their own eyes and in the eyes of others. When disability is thought of as something wrong with people it can be a frightening and disturbing thought to consider that this is a description that could be applied to oneself. In a social and economic environment based on competitive individualism to be perceived as being flawed can bring hard consequences. Holding it together, putting a brave face on it, masking the symptoms, might require much effort but still be considered worth it. As Harold Garfinkel suggests, the practices of everyday life 'consist of an endless, ongoing contingent accomplishment' (Garfinkel, 2008:1).

When it comes to managing to get by without drawing attention to impairment, much depends on how successfully 'masks of identity' are worn (Strauss, 2008). Judgements made about people and situations are always contextual in that they depend upon making 'interlocked discriminations' about what is going on. In conventional, everyday situations:

participants carry out required or expected sequences of acts. These are self-explanatory. They are understood by everyone involved as flowing from the nature of the situations and the conventional roles of participants (Strauss, 2008:49).

As long as Ben's grandfather successfully maintained the role of 'old man' and Helen's mother the role of 'General Practitioner', carrying out the required and expected sequences of acts associated with these parts, they were able to escape identification as disabled. Let the mask slip, however, or let evidence of impairment surface obviously, and they risked the possibility of that identity being brought into question. When impairment is marked as shameful incompetence this

justifies keeping it hidden where possible. As figures Ben and Helen looked up to, and from whom they learned, the lessons being taught by example are clear.

Returning momentarily to Hazel and Rose, it is entirely possible, indeed very likely, that there were more people with impairments – people like Ben’s granddad and Helen’s mother – around than appeared the case in the communities they grew up in during the 1960s. What is probable is that people with obvious impairments will mostly have already been removed from community life, while those with less obvious impairments will have been actively seeking – even if not always consciously – to distance themselves from this association and to blend in with the crowd.

The sense of distance I have outlined here is expressed by Ash:

It’s like living in two different worlds, it’s... the world of people in wheelchairs and the world... of people who can get jobs, get married, and... it’s getting closer, but I cannae see it getting... do you know what I mean... (l.364)

Isolation

Participants’ comments reveal that impairment and disability are frequently experienced as aspects of life that must be ‘suffered’ alone. People are left to make sense of this experience by themselves because others around them don’t want or like to talk about it. It is sensed that there is nobody else to validate personal thoughts and an awareness of not being able to talk about negative experience for fear of upsetting other people.

In order to be isolated, I would argue, it is unnecessary to be physically distant from other people. Recalling Elias, it should be remembered that in contemporary society people undergo intense training to experience themselves as individuals in the specific way they do. Elias describes the way that language functions as a tool to implant in people roots so deep that it becomes:

almost impossible, in speaking about the functioning and behavior of human beings, to avoid reifying spatial analogies like ‘inner life’ and ‘outer world’ (Elias, 2004:114f.).

The sense of standing in isolation, opposed to the outside world of people and things, and of being inwardly separated from what exists 'outside' is experienced as being self-evident and natural (Elias, 2001:114).

Roshni is eloquent in her description of the frustration she felt at the experience of missing out on many life events that teenagers might usually expect to come their way. While Roshni's anger expressed here is actually at having had nobody to talk with to make sense of her experience of blindness, its cause was experienced as being within herself.

Certainly when I went through my teenage years... I experienced a lot of anger and resentment... and I really wanted to let that anger out, and I really wanted to talk about the fact that I can't see, and this is fucking shit, and this is awful... this is really crap... I can't do so many things, I can't do the things everyone around me is doing... I'm not pulling guys the way my friends are, I'm not drinking behind my parents' backs, I'm not... there are so many things I'm not doing, and this is why I'm not doing them... and I don't like me, and I don't like life... but you can't say that within your family environment, and you can't... you can't say that to your sighted friends, cos they don't get it either... and you don't, certainly at that time, I didn't find a lot of affinity with my visually impaired friends, either... because most of them had some degree of vision, and their experience was very different from mine... erm... and of those who were totally blind (sighs...) I found them to be... they didn't have a lot of the aspirations I had, anyway, so they were quite happy playing with fuzzy felt and going to Blind Club... (l.1.384ff.)

Maurice Merleau-Ponty reflects that:

Consciousness holds itself responsible for everything, and takes everything upon itself, but it has nothing of its own and makes its life in the world (Merleau-Ponty, 2008:526).

While the structures that pattern experience cannot be seen their effects can still be felt. In the situation she describes above Roshni shoulders herself the blame for her situation.

Deborah Lupton suggests that emotionality locates the individual within the world of social interactions. Emotions cannot be experienced without the real or imagined presence of others:

While the emotions may be experienced as inner feelings, they are generated through interactions with others (Lupton, 1998:22).

Lupton argues further that emotional embodied experience should be regarded as active and agential rather than simply as a means by which the body is inscribed through discourse and practice. This is to say that emotions have effects in that they activate dispositions, postures and movements – ways of both doing and being – which are not only attitudinal but also physical (Lupton, 1998:37). It is in this sense that I want to argue that being disabled – regarded in a relational sense – can be understood as something that comes to inhabit the bodies, or becomes an embodied experience, of people with impairments.

If this sounds as if I am retreating into a medical or individual model of disability, I must emphasise that this is not my intention. I am suggesting that disability is an unequal social relationship imposed upon people with impairments (through physical barriers and social practices) which becomes embodied in physicality, in the thoughts and actions and reactions of people with impairments. Recalling Lola's description of her peers in the residential unit 'obeying the system, you know, like nodding dogs in cars, just going yes, yes, yes, yes... and doing their Buttons and Bows, and whatever...' (l.1:933ff.), it is, for example, in this submission to doing and being what is expected of them – in the nodding and in the performance of the movements involved in doing their Buttons and Bows - that people with impairments become disabled people.

The isolating impact of disability is also suggested in the social discouragement received by participants about identifying as disabled. Rose recalls a conversation with her husband:

...I said to my husband, er... "You know, do you think I ought to register?" ...and he said "No, because once you put that label on yourself then you *will* become disabled..." (l.1:200ff.)

Rose's husband's statement implies an acknowledgement of role theory which:

draws attention to the extent to which the experience of illness is bound up with the wider social context and... makes clear that the meanings imputed to illness can impact upon the experience and the identity of the sufferer (Nettleton, 1998:71)

Rose's husband suggests the possibility that the acceptance of a disabled identity will lead to negative changes in the way Rose relates to herself and that this will impact on how she relates to others. He assumes that identifying as disabled involves 'giving up'. Rose continues:

using a wheelchair is... a big step... when I first started using a wheelchair... it wasn't an electric chair, it was a manual one... and that means you have somebody pushing you... well, I wasn't able to push myself, anyway... and that begins to change the nature of relationships... and I think that might be when my husband... who no longer lives with me... labelled me, in his mind, as 'disabled'... (1.1.389ff.)

For Rose there is an association of the time she started to use a wheelchair and being considered by others to have given up. This was perceived as representing a defeat of character. To Rose's husband it appears to have meant they were no longer equals. To give in to disability was regarded as involving acceptance of a dependent and unequal status. Rose talks of the sense she felt that, from the moment he recognised her as disabled she was 'gone in his life' (1.1.619ff). After being told by her husband that he would actually rather she was dead than dependent on him (1.1:685) this resulted in an eventual decision to ask him to leave (1.1:589). The action she took, in ending their marriage and in voluntarily isolating herself, she perceived as necessary in order to preserve her selfhood. Talking about this experience, Rose made what I consider a very important comment:

it's about being made to feel, and feeling it... it's not just about being made to feel, but that you feel it... (1.1:578ff.)

It is in this sense that I want, while retaining a social relational perspective, to suggest that disability can be regarded as becoming part of a person's embodied reality. While hostility and prejudice are experienced objectively, they are felt subjectively. It becomes a matter of how these feelings are dealt with.

Please don't talk about pain

If, for the sake of preserving esteem in the eyes of others, it is considered important at least to make the effort to be seen as normal, it is more important still to avoid making reference to impairment effects such as pain or discomfort. Jennie recalls of growing up in South Yorkshire that:

when I was in my teens I started to have more serious health problems... erm... in relation to the condition that underlies all my illness... erm... I had menorrhagia... very heavy periods... which would cripple me, basically... because I would be anaemic... and I would be struggling to walk and things like that... one week out of four... erm... again, I didn't really think of myself as being disabled, but I was aware that I was on the receiving end of prejudice because of my illness, and... particularly because it was the type of illness that people won't talk about at all, because it's a taboo subject... to talk about menstruation... so, where I tried to discuss it with girls at my school, people laughed at me and wouldn't believe me... despite the evident fact that I was falling over one week out of every four... (1.1:161ff.)

A sense is gained that it is considered inappropriate to talk about impairment not just within formal or public situations, described by Erving Goffman as 'the front regions', in which an individual's performance is judged 'as an effort to give the appearance that his activity... maintains and embodies certain standards' (Goffman, 1976:110), but also to the 'backstage area' in which a performer can reasonably expect to be able to relax. Jennie further comments:

It reminds me of what I've been told... with regards to my sexuality in the past... I've had people say to me 'We don't mind you being queer, but you don't have to talk about it...' and I rather feel that with disabilities that people can't see there's sometimes an attitude of 'we don't mind you being disabled, but you can pretend it's not the case' ...it's convenient in polite society if you pass as normal... (1.1:297ff.)

Being told by friends and families, among whom it might be hoped one could drop the mask, that even here the subjects of impairment and disability are unwelcome for discussion, leaves little option but to turn these thoughts inwards.

Sometimes this message is made implicit by refusing to offer openings to begin to talk. Ash comments of family occasions in Midlothian that:

...sometimes relatives at... erm... family gatherings... they don't really ask me what I'm doing because I think they're a wee bit nervous to... they know I don't work, they know... it's not because of my physical disability that I don't work, it's because of my nervousness and that... that's what I believe, anyway, but they don't ask...

they feel nervous to ask “Well, what did you do yesterday?”... (l.1.865ff.)

In Surinder’s view it is not just in social life that disabled people are made to feel unwelcome, but within the family as well:

One of my family members has said to me “Do you *have* to use that walking stick? Do you have to...?” ...you know, they felt a sense of shame... they couldn’t acknowledge that this person related to them has a disability now... do you deal with your disability or do you deal with the emotions of other people who are directly related to you and... with Joe Bloggs out in the street, out in the community... (l.1.409ff.)

In other situations the subject is carefully evaded or, if acknowledged, quickly brushed over. Rose states that

(My friends) don’t have an understanding of the situation that I’m in... they are not comfortable asking... you know, if I don’t mention it, then they don’t mention it... they’re not really comfortable asking... one or two of them will say “Are you still walking?” or whatever... whatever it happens to be, and it’s like, if you say “Yes,” it’s... oh, okay, so everything’s fine, and it’s not... because you’re trying to overcome terrible difficulties all the time... (l.1.631ff.)

Sarah expresses the sense that disabled people are not expected to talk about their experiences for fear of troubling those around them:

I’d felt like I had to stay quiet and not say what I felt... because it would upset people, it would upset my mum and dad... it would upset... people out there who don’t understand... and just look at us and think that you’re disabled... (l.1.945ff.)

The knowledge of hurt experienced by disabled sons and daughters can be difficult for parents to take on board, especially if there is little they can see to do about this. Swain and French (1998) have talked about the difficulties of family relationships of care when there is perceived no way of understanding disability other than as physical limitation to be endured and overcome. Sarah’s strategy for dealing with this was protective: by not talking about her feelings she aimed to protect her parents from the upset that knowledge of her experience would bring.

An unwillingness to discuss disability within family settings may be seen as positive, the result of a conscious attempt to place emphasis upon the things a child can do rather than those they cannot. Eddie, a participant in research carried out by Tom Shakespeare, Kath Gillespie-Sells and Dominic Davies, states:

I was born with my impairment, I had four brothers, none of whom were disabled people...I was brought up believing I was the same as my brothers... which had its advantages which was not being mollycoddled. The disadvantage is I was never taught anything about disability and the wheelchair, about disability and identity (Shakespeare *et al*, 1996:50).

Family members may avoid talking about disability because they feel it is in the best interests of the disabled son, daughter or sibling not to do so. As Read (2000) points out, other family members are not automatically experts on disability, and can usually only act in what they perceive as the immediate interests of the disabled person. In Eddie's terms, from the point of view of the disabled person looking back, this can be regarded as incurring costs to be paid later when he encounters the world beyond the family as an individual on his own terms and finds his preparation inadequate for the barriers and discrimination he encounters.

Dona Avery suggests that families of disabled people can find themselves endowed with the stigma of disability through relationship (Avery, 1999:117). This implies that a reason for avoidance or denial of the subject may be to do with an attempt at personal disassociation. Not talking about disability is perhaps perceived as making disability less real. While this may work for other family members, it can, as Rose indicates, create a real sense of frustration:

I think I definitely try to put a brave face on it, and try and show the cheery side, and try to be positive, and try and get on with things... whatever they may be... er... you don't want to have to do that with your family... (l.1.675ff.)

Rose is saying that in her experience there is no backstage area where one does not have to keep up an act. Brian expresses anger he feels about not being able to be open about who he is with his family.

There's a tension... erm... within family... I'm not open to my family or to my partner's family... erm... I don't call myself a disabled person to their face... being open and more explicit in that context is just... opening up a lot of grief for myself... erm... my father has coped by being in complete denial... that's... and... to some

extent, you know, I spent... until my mid-thirties really, battling him... battling him and his denial... but there was just no point... but it's quite painful, really, not being able to be who I am... in my own family... it's fucking awful, really... in that sense... and it makes me feel quite resentful... (l.403ff.)

Ali describes the sense of anxiety he experienced at school in Whitley Bay at the time he became conscious of what was later identified as dyslexia, but during which he had neither words nor understanding to explain why he was having difficulties with learning:

I remember I used to get really, really frustrated and I thought it's just hormones, getting really angry... it was almost as if to say to the staff I've got a problem and you're not doing anything about it... and I remember, I did it for a good few months... and it was never ... the teacher never actually came back to me and talked ... you know... "Have you got a problem with anything?"... and I think that, at the time in my life when I was looking for ... maybe I *have* got a problem or maybe it's just *me*, I just can't do the work... you know, and because of that it led to this negative decline with me thinking I'm useless, I can't do anything... (l.246ff.)

When normality is constructed as an ideal for young people (Priestley, 2003), to come to a conclusion for yourself that there is something 'wrong' with the self is an isolating experience. To define yourself against the norm in terms of the stigmatised identity of disability will not seem an attractive proposition. While normality is presumed within a mainstream school context, abnormality will not be actively looked for. To have to deal with a dawning self-awareness of impairment that is unrecognised by others not only seems like a big thing. It *is* a big thing.

Cultural isolation

Surinder describes the isolation she has experienced as an Asian disabled woman who has had to suppress her ethnic identity because she has found few opportunities to feel accepted as a disabled woman within the Asian community:

there were no Asian places that I could go to where I could speak to people regarding the multiple barriers, rather than just the one... so I dealt with my diagnosis rather than my cultural identity... I kind of suppressed that because I

couldn't talk about it... I just stuck to the disability rather than looking at the disability *and* the cultural needs... because there was nothing there... (1.1:476ff.)

Speaking of her experience of attending a local authority day centre, she suggests the other disabled people attending:

were probably thinking what's she doing here... she should be with her own folk... (1.1:510ff.)

What Surinder describes here is a sense of rejection by the Asian community because she is disabled and a simultaneous rejection by the disabled community because she is Asian: leading not only to a sense of detachment from both communities but also clearly working against the development of a positive disabled identity. Describing the way that discrimination is experienced simultaneously at different points of identity, Ayesha Vernon and John Swain have observed that

the more overt the discrimination, the more heightened one's awareness and sense of vulnerability around that particular identity (Vernon and Swain, 2002:84).

Surinder's experience of isolation was made more intense by her sense of having to divide herself into distinct categories. Because at least services have existed for disabled people she attempted to fit herself within these, even though they were, in her words 'white-centric' (1.1:478). At the same time, this meant exposing herself to racist values, as expressed volubly by a local authority care worker who told her that 'all non-whites should go back to their own country' (1.1:286).

Surinder states that sometimes she is made to feel like 'the lowest of the low' (1.1:525):

not am I only disabled but I'm... and disabled people aren't recognized, but... you know... below that I've been placed as an Asian disabled person, who is certainly not recognized... one iota... (1.1:526ff.)

Restitution and 'the Sick Role'

As Jennie says, she 'gets sick' of:

people coming up and saying "Smile, it might never happen..." all the time... and thinking they can intrude in that way... if I'm just looking miserable... because it's my business if I'm looking miserable... I have turned round to these people a number of times and said "Well, I would smile... but it's a continuing hideous

pain...” (laughs)... “Do you want a taste of it, mate?” (laughs)... erm... and then they do tend to back away (laughs)... and shrivel up... (1.1:723)

Arthur Frank’s conception of the restitution narrative is useful in making sense of what is happening in exchanges like the ones Jennie describes. As Frank notes, contemporary culture treats health as ‘the normal condition that people ought to have restored’ (Frank, 1997:77). When impairment is identified closely with ill health there is always a cultural expectation that disabled people will aspire to ‘get better’:

The restitution narrative not only reflects a ‘natural’ desire to get well and stay well. People learn this narrative from institutional stories that model how illness is to be told (Frank, 1997:78).

Such institutional stories are those learned by Charles, Sarah, Roshni, Kevin and Mary in special school. They have also been learnt by Rose, Hazel and Surinder in mainstream community life. They are learned in the silence about disability as well as in the charity images. Surinder recalls:

I remember in school... we didn’t talk about disability... there was nothing discussed... erm ... I mean ... in hindsight, had we looked at that... we talked about sex education and we talked about ... erm ... the differences between boys and girls, but we didn’t talk about disability... (1.1.147ff.)

Cathy Reay draws attention to recent research at Leeds University identifying typical misconceptions held by schoolchildren:

disabled people are not able to work, they are unlikely to have a partner or get married, disabilities are passed on to children and disabled people have tragic lives, often cut short by their impairment (Reay, 2009:*unpaged*).

Reay quotes Angharad Beckett, leader of this study, as saying in regard to primary school education on disability: “Many schools are doing very little, sometimes nothing” (Reay, 2009:*unpaged*).

Frank discusses Talcott Parson’s theory of ‘the sick role’ which he describes as ‘a modernist narrative of social control’ (Frank, 1997:82). To summarise, the sick role involves granting a person identified as sick a temporary reprieve from social responsibilities providing they acknowledge the task to get well and return to the normal obligations of work and family as quickly as possible.

It could be argued that such a role has little relevance for many disabled people who will:

accept some level of illness as the permanent background and intermittent foreground of their lives (Frank, 1997:82).

This is to say nothing of people with long-term impairments which do not constitute sickness and who live healthy lives on a day-to-day basis. However, I would suggest that this role impacts on the lives of disabled people by marking impairment as a condition to be dealt with cheerfully and privately. Many disabled people find themselves placed permanently in the sick role even when they are not sick. Hence the disapproval Jennie experiences from people who consider she is not playing the part.

Simultaneously, other people with impairments are reluctant to acknowledge these for fear of being placed in the sick role. The association of disability with unwanted social status serves to ensure that people do their best to keep impairment hidden or to minimise its significance in terms of their everyday lives. Hazel describes the period leading towards the diagnosis of her condition:

I had, I suppose, reoccurring health problems for about two years... er, a few years ago... and one of the symptoms of that was just extreme tiredness... just no energy at all... and the doctor just thought it was my age... at the time I was in my mid to late thirties... and didn't really offer anything for me, and then I went home and thought it's in my head... I must be imagining the way I'm feeling... I used to go to bed at night and... I thought that I was having to remind myself to breathe... and then I really thought I'd lost the plot... because I thought how can you be lying in bed and feeling that you've got to remind yourself to breathe... and so I was convinced that I was just going round the hat rack, to be honest...and then left it another eighteen months of feeling absolutely exhausted, tired, no energy at all... I'd get in from work and think oh, I need to do the dinner, or I need to put the iron on to do some ironing, and then just lie on the settee... so for me, when I eventually got a diagnosis, it was a huge relief... because I knew I wasn't mad... (l.1:156ff.)

Faced with an initial diagnosis of health, Hazel felt unable to draw attention to her symptoms but rather experienced these as something to be dealt with privately. Fulfilling her expected personal roles involved getting on with life, going to work and doing the housework, continuing to carry out tasks she found increasingly exhausting. Insofar as she considered her experience might be one of disability, this was only in terms of imagining herself 'going

round the hat rack'. Her relief at being diagnosed with a medical condition is expressed, not only because it meant that she could start to receive treatment for her condition, but also because her own experience was validated.

I suggest that in a disabling society impairment can only be acknowledged if it is medically diagnosed, an experience which draws the self into discourses which name impairment as defect. Ali's comments here further illustrate this point. For Ali, disability is associated with a sick role with which he does not identify. He states his desire to reject identity as somebody who has an impairment:

I really ... deep down... I like to think I don't have a disability but ... I've had more ... I had another test just to confirm it again for my job that I just had and ... I jokingly said to this work psychologist when he told me I was dyslexic... erm ... "Have you made that up?"... and he said... "Oh no, you're dyslexic ... you have classic dyslexia..." but ... erm ... I think ... deep down I still think that I haven't got a disability (l.1:529).

Tanya Titchkosky's description of the cultural expectation that 'people should simultaneously be and not be disabled' (Titchkosky, 2003:76) is helpful here:

Getting as close as possible to 'normal' standards of bodily engagement... is a cultural expectation of disabled persons and assures that normalcy maintains its status as a dominant but taken-for-granted phenomenon. This expectation... also leads to normalcy as able-bodiedness remaining an unexamined social ideal (Titchkosky, 2003:76).

The tension experienced by Ali is one that involves measuring himself against the social ideal of normalcy and finding himself wanting. Because it is so clearly understood that disability is a shortcoming when measured in these terms he is uncomfortable about accepting dyslexia as part of his identity. When dyslexia is measured and considered only as a deviation from 'normal-thinking' then the ground for considering this as 'useless-difference' is established (Michalko, 2002:97).

Conclusion

Internalised oppression is a term that has been used by numerous writers in Disability Studies to describe something which happens:

when individuals in a marginalised group in society internalise the prejudices held by the dominant group... This form of oppression is most effective when acting at the subconscious level, affecting the self-esteem of the individual in addition to shaping their thoughts and actions (Reeve, 2004:87).

While disability is characterised by the social model as ‘something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society’ (UPIAS, 1976:14), there is involved an implication that disability is always something *done to* people with impairments. There is also implied a passive reception, as if people with impairments will inevitably be disabled. Drawing upon Reeve’s definition of internalised oppression, I want to argue that disability can also be thought of as something that people with impairments act out or perform. Disability is a form of oppression which acts at the subconscious level, shaping the thoughts and actions of the individual with impairments. However, it is certainly not the case that all people with impairments are disabled or that all people with impairments who are disabled are disabled all the time. I suggest there is a need to recognise the possibility for agency.

I draw here upon Judith Butler’s arguments identifying gender as performative:

There is no gender identity behind the expressions of gender; that identity is performatively constituted by the very ‘expressions’ that are said to be its results (Butler, 1990:25).

I would argue that we can similarly understand disability as performatively constituted. If, like gender, disability is performatively produced and compelled by regulatory practices (the experiences of Charles, Lola, Mary, Kevin, Sarah at their special schools are illustrative here) then it can only be seen in its effects. There is an important distinction between stating that disability is compelled by regulatory practices and that disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. The former statement suggests active intent; the latter only necessarily suggests omission to include. Disability is about more than just about what people with impairments cannot do and be, it is about what people with impairments *are required* to do and be.

Borrowing a term from Simon Charlesworth, I want to suggest that disability is an oppressive relationship that is *encountered* (Charlesworth, 2000:90). Encounter with disability involves being situated within

definite contexts of meanings carried in the ineffable details of the comportment we acquire from those around us, through which the world becomes meaningful as a subjective space (Charlesworth, 2000:90).

This is why segregation is so important. Even while, as Mary and Charles have told us, the word disability is hardly ever mentioned, it is within special schools that the first lessons in becoming disabled are encountered: to become disabled is to learn to desire above all things the achievement of normality while being made aware by one's location just how far beyond one's reach this goal is. Outwith special schools, also, parallel lessons about disability are learned: 'the disabled' are frightening. Andrew Collins, in his memoirs of 'growing up normal in the 70s', recalls that one of his teachers, Mrs Munro:

had a mentally and physically handicapped son called Steven whom she occasionally brought into school just to scare the life out of me (Collins, 2003:67).

The 'ineffable details of the comportment we acquire from those around us' Charlesworth speaks of include the actions, gestures, and attempts made by people with impairments to prove just how 'normal' they are. Disability involves people with impairments being taught to want to act, and wanting to act, and attempting to act in ways which conform with social expectations of people who do not have impairments; which are regarded as customary and appropriate in order to participate in the social mainstream. It also involves a disavowal by people with impairments of ways of doing things which might suit their physical, sensory, emotional or intellectual needs and a sense of shame and inadequacy when such ways of doing things are necessary or unavoidable, in private as well as in public.

Roshni recalls that:

I always used to think that living and being and acting like the non-disabled person was something I should aspire to... and something that I should try to do... so I remember for example when I was doing long cane training I would always be very conscious of not... you know... there are different landmarks and different positioning techniques that you use to navigate as a visually impaired person... so maybe like if you're walking along a street you keep to the wall, for example, so you're aware of when the wall turns and you have a corner... or when a road crossing's coming up... those kind of things... but I would always, always, always walk down the middle of the pavement... I would never, ever... and because of it I made so many errors... and I would miss some of those landmarks... in terms of crossings and turnings and things... and my instructors would always say... but why

do you do this... this is... you can do this but you make very obvious errors... and what I could never admit then was the fact that it was just because I just wanted to look as 'normal' as possible... I didn't want to be seen as this blind woman that had to grab onto the walls and follow them along... (1.3.286)

For a person with an impairment to perform a life function or task in her own way, to get from one place to another in his own way, to communicate with a friend in their own way, to access information, to make herself understood, none of these makes a person disabled. Disability is only perceived when such things are measured against socially valued ways of achieving the same ends. Disability appears when, in order to gain approval, doing things in ways that work is discouraged by others or eschewed by self in favour of attempting to do these things in ways that suit other people.

Much of this is already socially known. This way of thinking is acknowledged and formally sanctioned in the requirements of the Disability Discrimination Act (1995) (DDA) and DDA Amendment Act (2005) for employers to make 'reasonable adjustments' in work practice to avoid placing disabled employees at a substantial disadvantage in comparison with non-disabled employees:

The most important thing to remember is that treating everyone the same does not mean that you are treating everyone fairly. The DDA requires people to be treated differently according to their needs by making reasonable adjustments for them (Employers' Forum on Disability, 2009: unpagged).

Carol Thomas argues that as well as the social barriers recognised by social modellists as externally imposed restrictions of activity:

there are also social barriers which erect 'restrictions' within ourselves, and thus place limits on our psycho-emotional well-being: for example, feeling 'hurt' by the reactions and behaviours of those around us, being made to feel worthless, of lesser value, unattractive, hopeless, stressed or insecure (Thomas, 1999:47).

In order to address the omission of personhood or agency that she identifies as lost in the materialist social model, Thomas offers a reworked social relational definition of disability:

Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engineered undermining of their psycho-emotional well-being (Thomas, 1999:60).

What I find compelling in Thomas' definition is her re-incorporation of disability as part of embodied experience. This is a position which allows us to speak of disability as being something from without which, in a sense, comes to possess individuals: in so far as names and identities are socially given and privately owned or resisted, this sense of being disabled is one that is felt and lived out in everyday practice. People with impairments are not just socially oppressed by physical and social barriers but respond to these as emotional human beings.

I want to move beyond Thomas' position to suggest that disability is a personal and social role imposed on people with impairments. Understanding disability in this way we can think of it as something acted out in the social contexts in which people with impairments find themselves located. It is a part people with impairments are expected to play which is fixed by the roles and identities of those around them situated as non-disabled people, whether these are closely connected to them, for instance, family members or disability industry professionals; or others whose influence is more distant and impersonal, such as media producers or celebrities with whom para-relationships are held (Turner, 2004).

As Sheldon Stryker notes, roles underlie the stability of social structure (Stryker, 2002:76). The role of disability, as materialised in and lived through the embodied experience of people with impairments, has a functional purpose in stabilising and maintaining existing patterns and relationships of social interaction within contemporary society. I am proposing here that disability is a role that validates the subject position of being normal or non-disabled by invalidating the lived experience of impairment in terms which mean that this can only be experienced as personal tragedy.

Such a role becomes difficult to escape other than in terms which explicitly address disability *as* a role because any other form of response involves compliance *with* that role. Narratives of overcoming and restitution validate the ideal of normality as effectively as those of passive dependence. Distancing the self from the idea of disability or from disability identity involves affirming the supposition that to be socially located as disabled is undesirable. The personal disavowal of status as disabled is an intrinsic part of the disabled role. As Sarah puts it:

I don't think I have accepted (that I am a disabled person) to be honest... saying that's a bit weird, but to be honest, I don't think I have... because I still get pissed off... and it's not like I don't accept it like I hate it, it's just that... I'm never going to be comfortable with it, I'm never going to be... erm... sort of, what people

expect...I suppose that's why I've done so many things like... that people go 'wow!' ...cos people just don't assume... and I certainly know that's the reason I did the sky-dive, it was just cos, like, I wanted to do something totally random and, like, just... something completely... I'd always wanted to do it, but it was, like, people said "Oh, I don't know if she should do it" ...so I thought fuck it, I'm going to do it... (1.1:694ff.)

Ben makes a similar point:

...all these things, so deeply engrained with me, unfortunately, you've gone through an entire childhood like that, you still tend to try... and reject a lot of support quite often... and you think you can do something which you... erm... no, you think you can do something which is impossible... but, you know... I have been, it's so deeply engrained it's just that you can't get rid of that attitude... even though you know it's a wrong and bad attitude... it's... it is part of my past identity... you know, you still feel you've got to out-compete other people... proving is passing, that's what I was looking to say... I still feel that I've got to prove myself... (1.539ff.)

The imposition of the idea of impairment and disability as personal deficiency is resisted by those who do not consider themselves personally deficient, but unless this resistance acknowledges the structural relations which are served by this idea, it is empty protest. To say "I don't see myself as disabled" (Anne, 1.1:162; Ali, 1.529; Hazel, 1.1:216; Sarah, 1.1:694) does not mean either that one does not experience social barriers or that one is not considered disabled by other people. However, it does involve a distancing of self from disability as an identity, which confirms the idea that to be disabled is not something one would want.

If we accept this understanding of disability as role we can begin to think of disability as part of the embodied experience of people with impairments, materialised not only in their exclusion from ordinary community life but in terms also of what they are expected to do with their lives instead: not just in terms of being passive (as recipients of charity) but also in attempting to demonstrate that they are not passive (by doing sky-dives).

As Stryker notes, the language of roles cannot be used without at least implicit reference to counter-roles (Stryker, 2002:58). From a culturally dominant perspective, the counter role to being disabled is understood as that of being able-bodied. Able-bodiedness and being non-disabled can be understood as descriptions of the same subject position but viewed from

within different discourses. While a hegemonic discourse equates able-bodiedness with normality, Simi Linton notes that within the disabled people's movement the term 'non-disabled' is used to describe the position of those who do not experience disability as oppression, a strategic use of language which centres disability in order to look at the world 'from the inside out' (Linton, 1998:13):

centring the disabled position and labelling its opposite non-disabled focuses attention on both the structure of knowledge and the structure of society (Linton, 1998:14).

The invalidation of impairment serves to bolster the able-bodied role, to reinforce the naturalness and desirability of this position. Within contemporary capitalism there is a requirement to purchase goods to meet basic needs and, therefore a dependency on employment which, in Lodziak's words, 'exerts its own material manipulations on needs and consumption' (Lodziak, 2002:93). Social imperatives like getting and keeping a job ensure that 'strategic image-presentation' (Lodziak, 2002:58) is a major human pre-occupation and has become identified as a need. Conformism is compelled by the actual working conditions in society (Lodziak, 2002:93). The disabled role involves validation of the subject position of being non-disabled because it involves acting out impairment, conceived as inadequacy and incompetence, striving to be something it is not: able-bodied. It is a role which confirms the position of able-bodiedness as neutral, normal and natural.

If the social structure is shaped by interaction, it is social structure that shapes the possibilities for interaction and so, ultimately, the person. Conversely, if the social person creatively alters patterns of interaction, those altered patterns can ultimately change social structure (Stryker, 2002:66).

I suggest that in order to begin to change social structures as these exist to shape the experience of impairment there is a need to awaken from what Bourdieu describes as 'the somatisation of social relations of domination' (Bourdieu and Wacquant, 2007:24):

People are 'pre-occupied' by certain future outcomes inscribed in the present they encounter only to the extent that their habitus sensitises and mobilises them to perceive and pursue them (Bourdieu and Wacquant, 2007:26).

While habitus is creative and inventive, this is within the limits of its structures which are 'the embodied sedimentation of the structures which produced it' (Bourdieu and Wacquant,

2007:19). Once it has become possible to step back and recognise those structures *as* structures, it becomes similarly possible to try and act upon these structures.

If we grant that symbolic systems are social products that contribute to making the world, that they do not simply mirror social relations but help constitute them, then one can, within limits, transform the world by transforming its representation (Bourdieu and Wacquant, 2008:14).

This is what has been achieved through the social model of disability, a transformed representation of the world which has made it possible to regard disability as an oppressive relationship, or as a structure of domination, rather than as individual limitation. The adoption of this model by the disabled people's movement as an organising principle has enabled a start to be made in transforming the world in terms of opportunities for the participation of people with impairments in ordinary life.

I suggest that the affirmative model can similarly be used as an analytical tool for transformed representation of the world in terms of describing the function that disability as role has to play in sustaining established social relations. To this end I propose the following affirmative model definitions:

Impairment:

physical, sensory, emotional and cognitive difference, divergent from socially valued norms of embodiment, to be expected and respected on its own terms in a diverse society

Disability:

a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those identified as non-disabled

My revised definition of impairment builds upon my analysis of participants' recollections and insights in that it includes a recognition and rejection of the social and cultural processes by which impairment comes to be marked as personal tragedy. While I have represented impairment as an individual characteristic of difference to be expected and respected on its own terms, this definition does not relate to normality as an established medical fact but to normality as something that is socially valued. Discussion of impairment can therefore, within the terms of this definition, be framed within social and cultural rather than medical terms.

My revised definition of disability takes into account participant's descriptions of their experiences of being actively turned into disabled people. It recognises the ways in which disability does not just exclude, but places a requirement on people with impairments to behave, think and speak in ways which acknowledge the superiority of normality and acquiesce in their own oppression. Disability is a role imposed on people with impairments in order to strengthen bourgeois social relations.

If the disabled role convinces people with impairments that the only way of achieving valued future outcomes is through overcoming their limitations as individuals, then however successfully this is achieved on personal terms, disabling social structures will remain unaltered. People who have overcome profound impairment effects may be held up as role models or inspirations, but leave disabling social structures untouched. This can be illustrated, for example, by considering the Paralympic games and the way that disabled athletes' expectations and motives are shaped by cultural body norms and social expectations. As Marie and Brent Hardin observe, Paralympic athletes:

reflect the force of great cultural pressure to accept the supercrip ideal and to reject ideas that might hold society more accountable (Hardin and Hardin, 2008:32).

This is expressed slightly more caustically by Simon Stevens, who suggests the Paralympic Games:

just represent the rehabilitation movement on a grand scale. What we are actually celebrating is a specific kind of day care of disabled people, but a bit posher (Stevens, 2008:10).

I conclude this chapter with a statement made by Kevin:

Even when I started work I didn't like going home... I used to go in the pub every night... did that for about four and a half years... drink, drink, drink... drink lunchtime, drink afternoon, drink evening... I never had any friends in the pub... I just used to drink myself stupid every day... stupid, really... all that money I've wasted... (1.1:980ff.)

Kevin expresses here the absence in his life of any emotional connections or involvements outside the pub. Nor did he have any emotional connections or involvements inside the pub. After leaving special school he avoided interaction with other people because of a profound sense of inexperience and awareness of his lack of social skills. The world did little to

encourage a closer acquaintance. Disability is not just about what people with impairments are excluded from doing, but is about what they are required to do instead.

Simon Charlesworth notes that:

An individual knows without much deliberation the range of the possible... We are not simply in the world, we are amidst it, our world comes to inhabit us because we come to know it through our socialisation into a way of being that discloses the world in a certain way... (Charlesworth, 2000:91).

Chapter 5: Disability as Role

Introduction

In this chapter I continue discussing themes raised by participants during the first series of interviews. This leads me to explore ways in which disabled people participate within mainstream disability discourses or, alternatively, within what Foucault has termed *reverse discourses* through which impairment is beginning to speak on its own behalf to demand acknowledgement of its own ‘naturalness’ (Foucault, 1998). I do this in order to consider the validity of my suggestion that disability can be regarded as an invalidating role in the context of a continuing discussion about the affirmative model.

Intrusion

For some participants initial identification as disabled was experienced in relation to eligibility to receive benefits. Recognising the self as disabled, then, can be associated with a practical orientation to being in the world. It is something one does to get by. Helen recalls an awakening association in her mind:

a friend of mine said to me... you can apply for benefits now... and I said don't be ridiculous, and she said no, seriously, you can probably apply for DLA and all sorts of things on the grounds of your mental health problems... and only then, once I'd applied for those, was I oh, right, yeah, that does mean I kind of... and then I began to realise that I'm classed as disabled, if that makes sense... (l.325ff.)

Helen's following comment reveals a perception that identifying as disabled involves coming to recognise oneself as fitting in to a pre-defined role within a system.

...but now that I have these specific labels it means that I can fit in to a lot of different categories and... I guess the difference to me is that... erm... and it feels like you're kind of playing the system in a way... even though you're not... and if this is written officially on a medical book or paper, then you can apply for certain benefits and things, and when you're applying for a job you can tick the yeah, I'm disabled box, and get the... you know... (l.1:376ff.).

The disabled role is established. Helen's words indicate that all that is required is the characters to play this role. While she speaks of feeling as if she is playing the system, the system draws her in.

Surinder is frank in describing what she saw as the benefits of being classed as disabled:

...then I thought well, I am a disabled person... great, that means I can get some help with all the things I need help with, like I don't need to go walking miles, I can get a parking permit... so there were some advantages to it... (1.1:353ff.)

Rose highlights the fact that for her accepting disability as a personal description was more a pragmatic issue than one which, on the face of it, involved identity issues:

..I still didn't think of myself as being disabled... as being a member of what I now like to think of as the disability community... I was still, more, I think, a member of... the whole community and culture... what I wanted to do to... er... try and start getting help with... er... things like ramps, and walking sticks and... er, parking discs and so on, erm... was to get myself registered as a disabled person... (1.1:189ff.)

Tension is experienced here because an unspoken agreement takes place that acceptance of entitlement to benefits involves acceptance not just of a description as disabled but also of the disabled role. While entitlements are gained which go some way towards addressing the realities of living with impairment in a disabling society, this position involves an acceptance of the view which states that impairment is unfortunate individual circumstance.

“I see myself as a person with...”

I would see myself as a person with a visual impairment, not a visually-impaired person... (1.784)

In this statement, Roshni places her sense of personhood above her sense of being disabled and situates herself as a subject of what Rod Michalko has called ‘person-first’ ideology (Michalko, 2002:10). Impairment is downplayed and regarded as distinct from her primary experience as a person.

Suggesting that disability is merely a secondary feature of one's identity and that we are persons first and persons with disabilities disavows both deviance and disability. It refocuses attention from the disability to the person who happens to have it (Michalko, 2002:11).

Person-first thinking is supported strongly by public services and charities on the supposition that it represents a step forward from traditional discourse which suggested impairment is the single most important thing about disabled people. This is illustrated in charity marketing slogans such as:

See the person, not the disability (Scope, 2007).

While well-intended, such expressions can be regarded as implying that trapped within the flawed body of each disabled person there is a (presumably healthy and normal) true self (Cameron, 2008). It is suggested that impairment is something requiring to be overlooked in recognising the person.

The pervasiveness of this way of thinking serves to spread confusion in relation to disability identity, reinforcing the idea that disabled people have a responsibility to downplay their impairments. Talking about the distance she has maintained between herself and disabled activists, Rohni describes:

...one of the reasons why, over the years, I have found it difficult to forge relationships with certain disabled people... their disability comes first...
(1.1.1052f.)

It is possible Roshni has misunderstood the way many disabled activists have represented themselves. Confusion can arise when the same commonly-used word (disabled) is used simultaneously to mean different things within different theoretical frameworks. I would suggest the self-characterisation of disabled activists as *disabled people* rather than as *people with disabilities* has been not so much to do with emphasising the primacy of impairment as a defining characteristic in their embodied experience as with emphasising the experience of disability as an oppressive social relationship. Scott-Hill's observation on disability as 'master identity' is useful here:

Disabled identity also tends to be regarded as 'the master identity' of the social – the category through which all other social identities are to be negotiated (Scott-Hill, 2004:90).

Scott-Hill's point is that once disability identity has been adopted, experience of all other identity categories often comes to be viewed through this prism. The oppressive impact of disabling social relations is regarded as shaping the ways in which all other aspects of personal identity are experienced. Thus, for example, one identifies as a *disabled* man, a *disabled* lesbian, a *disabled* black woman, a *disabled* person with the learning difficulties

label (Aspis, 1999:182). While a recognition is involved here that one's sense of self in these other terms is always mediated by the distorting and oppressive impact of disability, it is relatively easy to understand why Roshni has understood this position as emphasising impairment above other personal characteristics.

I don't see myself as a disabled person

Statements along the lines of "I don't see myself as a disabled person" were made by a number of participants, though for very different reasons. These I would summarise as, firstly, unwillingness to identify with other disabled people for fear of being socially classed as belonging to or with them; and, secondly, unwillingness to identify personally in terms of a socially oppressive category.

Talking about her experience after losing her limited hearing and becoming deaf in her early twenties, Anne recalls the period after leaving hospital:

At the time I went back into the world, two months later, I was fine... and I was back with my friends... nothing had changed... same job, same work, same friends, same social life... just I wasn't hearing... yes... basically I wasn't prepared to change my life... I wasn't prepared to become something that I wasn't... er... that I didn't see myself as... so it was basically an issue of tenaciously hanging on to my life... I wasn't going to... was not prepared to change my life... (l.1:256ff.)

As far as Anne was concerned, she refused to be placed in the role of 'deaf woman'. She did not want deafness regarded as her primary defining characteristic, but wanted to be recognised as a young, outgoing professional woman *who happened to be deaf*. She is emphatic about the importance of her own individuality:

I don't want to be shoe-horned into anything other than who I am... Anne... I don't want to be shoe-horned into them... because my life is so much more than disability... (l.614ff.)

In Anne's situation this is not about denying the significance of deafness within her life. For example, she talks about practical consequences in terms of carrying out day-to-day business:

...my deafness is part of me... I won't say it's a small part, because it does impact on me... I must have teletext... I can't just pick up a mobile phone and call somebody... I must text them and hope that they respond... or I have to find a

minicom... but these are just... you just build them into your life... (l.1.382ff.)

Anne identifies negative consequences in terms of being both disabled and hearing impaired:

I get a bit annoyed with not having subtitles at the cinema, things like that... you think “Oh, bloody hell, this is...” ...in other ways it’s not a huge thing... sometimes if I sit and think about it, I think yes, I am missing out on an awful lot of things... in terms of music... or picking up 99% of the conversation as opposed to 60% of it... er... it’s quite annoying when somebody’s standing behind me saying “Excuse me...” and they think I’m rudely ignoring them... when, of course, I’m not rudely ignoring them... I don’t know they’re saying “Excuse me...” (l.1.182ff.)

However, having acknowledged these issues, Anne insists that for her deafness is not a primary identity:

I find it hard to... distinguish me as a deaf person from me... because it’s just part of me... it’s just part of a bigger thing... I can’t just focus on that one thing... (l.304f.)

What Anne says about herself, in terms of her reluctance to identify as disabled, appears on the surface to involve rejection of the idea of group identities in general as opposed to simply group identity as disabled:

I use the term ‘impairment’... because I don’t really consider myself disabled... because that’s a community I don’t particularly want to belong to... in the sense that I don’t particularly want to belong to a community... I’ve no need... and that could be because of my colour, it could be because of my gender, it could be because I can’t hear... it could be anything... but I don’t particularly want to be segregated based on anything like that... I’m me and I am an individual... so let’s talk about me as an individual... (l.1.162ff.)

The question arises here about whether identifying as a white woman would involve the risk of disaffirmation in quite the same way involved in identifying as disabled. John Swain and I have commented on the fact that, as for gay men and lesbian women, there is a coming out process for disabled people which involves a declaration of identity outside the norm (Swain and Cameron, 1999:68). Where normality is presumed, those aspects of a person’s identity considered normal are unlikely to present themselves as areas for introspection and anxiety. Group identity as disabled is more likely, within contemporary social arrangements, to involve stigma than group identity as white or as a heterosexual woman.

Again this involves us in asking questions about the meaning of disability. Simon Stevens ponders the question *how disabled am I?*

Sometimes I go out and everyone seems to understand what I am saying and I look back at the day and ponder whether I really am disabled. At other times, no one seems to understand what I am saying or I face outright disablism (Stevens, 2009:10).

If Anne's experience is that the majority of her interactions are free from judgements which diminish her sense of self or limit her opportunities for agency then perhaps, after all, she is not disabled. If, in her actions, thoughts, internal conversations, relationships and exchanges with others, her deafness is simply not an issue, then it may be possible to argue this. On the other hand, her following statement implies a recognition of impairment effects and disabling barriers created by other people's lack of awareness:

Don't get me wrong, it's not all sunshine and light... I have really bad days, when I think, you know... God, I really wish I could hear music today... er... or getting fed up with mumblers... having said that, I work with people who go *whisper whisper whisper* and I think "Oh, God, they're mumbling and they can hear perfectly..."...I just can't be bothered listening to them, because they keep mumbling all the time... obviously for me it makes life harder... (l.1.363ff.)

It would be possible to argue that Anne's experience in terms of resistance to the disabled role has to do with the age at which she became completely (as opposed to partially) deaf, in that she had already constructed a self-identity on the basis of competence rather than one shaped by others' perceptions of personal limitation. It could likewise be argued that class identity and the previous acquisition of personal and cultural capital had equipped Anne with the confidence and self-belief to resist the disabled role. Yet the comparable example of Rose would suggest that these in themselves are not sufficient explanatory factors. There is no simple correlation between the age of onset of impairment or social class and the way in which disability will be experienced (Barnes, 1996). However, paradoxically, it can be said that Anne's determination to succeed *in spite of* being deaf will have received social approval as conforming with the disabled role.

A different reason

A related, though very different, reason for avoiding identifying as disabled is given by Mary:

Should we view ourselves, if we are disabled... as that being a positive term... and I don't think we should... erm... cos to me disability and racism are the same things... you know... do I want... if I were black, right, or B.M.E.... would I want to say oh, I'm a person who experiences racism and only to be defined in those terms... no, I don't want to be defined by the horrible thing that happens to me... that's why I don't particularly want to be defined as being a disabled person... a person with an impairment, yeah... I'm cool about that... (1.1.575ff.)

Mary recognises disability as a social relationship but states this is something she feels uncomfortable about taking on as an identity. What makes this complicated is that while on first sight it might appear as if some of what Mary is saying here is virtually the same as what Anne, and Roshni earlier, have said, there are subtle differences. When Mary states that she is 'cool' about being recognised as a person with an impairment she is stating that she feels fine about having her visual impairment considered a primary part of what makes her Mary. She is not stating that she is a person first who happens to have a visual impairment, but that to her being visually impaired is a valued part of who she is. When she states that 'I don't particularly want to be defined as a disabled person' she is making a statement from a position which distinguishes between disability as imposed oppression and disability as personal characteristic. She rejects disability from a position which defines disability as oppression rather than from a position that wishes to downplay the significance of living with impairment.

The important distinction to be noted is that, in rejecting disability identity conceived in personal terms, Anne and Roshni comply with the requirements of the disabled role. In conceiving of this in social relational terms, Mary sets herself against these requirements.

You're asking me how I feel about other disabled people... actually, most of them are a fucking pain in the arse... you know, that's how I feel... all they want to talk about is their own experiences... within the medical model... and, generally speaking, what terrible lives they have... right... why do I get so annoyed about this is because it never moves on from that... I think there's a real level of false consciousness... in the majority of disabled people... now... this is where I'm going to have to be nicer and more understanding... given the dominance of

mainstream culture and the way it portrays us, it is almost inevitable that people will have a level of false consciousness around impairment and disability... and around their own experiences in society... right... what really annoys me, though, is it's not actually inevitable... you don't have to live in that state of false consciousness for all your life... you can break free from it... (l.1:861ff.)

While other participants act out the disabled role by resisting identification as disabled, Mary rejects the disabled role as ideological imposition. In affirming her identity as a woman with a visual impairment, she transcends the disabled role by refusing to recognise impairment as something to distance herself from. This does not mean that all of a sudden her life is wonderful, but it does mean she can understand her situation in a new light.

Unwanted interference

The paradoxical nature of disability is reflected in the fact that, while the experience of isolation has been identified as a major source of tension, so also is unwanted interference. This can be experienced in many ways: receiving sympathy from relatives or family members; pitying glances, comments and overly helpful offers of assistance from strangers; professional officiousness and condescension.

Rose talks of:

an aunty of my husband's who always comes on the phone and says (*in overly sympathetic tones*) "How are you dear? And how are you managing? Oh, you're so brave..." (l.1.615ff.)

In these remarks, her ex-husband's aunt re-states the respective roles involved in being disabled and non-disabled. Rose finds herself cast in, and unable to move beyond, the identity of sufferer. I did not ask Rose but, as she is in her fifties, presumably her ex-husband's aunt will be at least in her seventies. In terms of social roles, this involves a reversal of the relationship she might ordinarily be expected to have with an older lady.

Helen talks of receiving what she considers inappropriate sympathy from her grandmother:

...it's also seen as really tragic if you've got something wrong with you when you're young... and the thing is, to me, I don't... I can't imagine being another person, because this is all I know... I don't see it as a tragedy, I just see it as a fact of life that I've got to get on with... and I do not want people feeling sorry for me... cos that doesn't help anyone, it's just annoying... I am who I am, and you going "Oh,

never mind..." does not improve things... it just makes me want to slap you, which is not going to help anyone... (laughs) ...and my gran says "Oh, it's such a shame, you having to deal with all this at such a young age..." ...and I'm like is it any better that my mum had to deal with this in her forties... or my granddad in his sixties... it's not any better or worse, it's still difficult... (1.965ff.)

As Helen says, receiving pity does not help, it is just experienced as annoying. It could be suggested Helen considers being cast in the role of young tragic victim a bigger problem than her emotional impairment. This she sees as 'a fact of life and something I've got to get on with'. It is not her impairment that she sees as the issue, but the response to her impairment.

In the following two extracts Jennie describes situations in which the intrusion of people who know her or slightly know her and of complete strangers can be experienced as irksome:

People do the wrong things, too, quite often... people assume, you know, that they should help me on with my coat... my arms don't bend properly because of my illness, so when somebody tries to hold my coat for me, I can't get into the coat, even if I want to... and people will... I'll say "Please, no, don't do that, just give me my coat"... and people will try to insist, which is really obnoxious (laughs) ... (1.1.131ff.)

Here we observe Jennie regarded in the disabled role as somebody who is dependent and expected to benefit from other people's kindness. What makes this role inescapable is that in protesting against unwanted help, Jennie will be regarded as protesting her ability to put on her coat herself, thereby reinforcing the expectation that disabled people are always preoccupied with proving their normality.

When I've had real problems bending my right leg at all, or problems walking because of that... a lot of the time I've tended to wear long skirts... because, being long skirts... loose ones... they cover it up... it means I can go about without looking overtly disabled... and I feel safer on the street like that... not necessarily because I would expect to be attacked for being disabled or anything... but because I expect to be attacked anyway... and I'd rather not look extra vulnerable... erm... but, you know... there are times when I've just got sick of that and worn a really short skirt... and had a leg that obviously doesn't function properly (laughs)... and people will tend to sort of gape at me... and I've had a lot of old men come up and

make passes at me in that situation... and tell me how brave I am (laughs)... not necessarily in a patronising way, but... more in a sort of awed-by-the-fact-that-somebody-would... that I would dare to do that... and I think that's made its own kind of impact... (l.1.695ff.)

Jennie's decisions to wear a short skirt can be read in terms of attempting to escape the disabled role. However, the difficulty of doing this is highlighted not only in the fact that 'people will tend to gape' but also in that she is applauded by leering old men for making the attempt at all. To be seen to be trying to overcome personal limitations is regarded as behaviour to be commended.

The way you perceive yourself is partly the way other people perceive you... and if you have people coming up to you in the street and saying "Are you enjoying yourself racing along... who's got the fastest wheelchair...?"...and just approaching you, where they wouldn't dream of approaching other strangers in the street... (l.1.805ff.)

Rose describes the way that inappropriate intrusion can impact on self-identity. What she speaks of here is a form of infantilisation, an establishment of power relations which equate the disabled role with a child role. What is not seen when such remarks are made by non-disabled strangers, presumably intending to be humorous, is the context of Rose's life: in which, as a result of their reactions to her impairment, her husband has gone, her daughter is in denial, her friends are not interested. As she says elsewhere:

Even if I was... of equal value... er, in your own eyes... to know that you are not of equal value in, er... other people's eyes... er... influences your perception of yourself... (l.710ff.)

Describing situations she has experienced when going out with an ex- boyfriend who is also disabled, Sarah expresses a sense of frustration at being unable to escape the disabled role:

...when we went out as well, when we went out as a couple, people would look at us and, like, they'd never say it, but you could see it... "Aww... isn't that a shame..." it's like, fuck off... fuck off, you know what... and it would be like... just like stupid things, like, you'd go into a restaurant and stuff, and it'd be like "Oh, is there someone with you..." ...like... why can't you see us just like any ordinary couple going out... why is there this big palaver which then makes us feel more...

abnormal, if you like, and more attention brought to it... and you're just... it's like, fuck off... you know what, I don't need this, fuck off... (1.658ff.)

Sarah's comment suggests there is no respite anywhere. The query "Oh, is there someone with you..." (like Mr McHenry's to me at the railway station) indicates puzzlement at the fact of disabled people being unaccompanied by a carer. In this context, too, it is possible that there are assumptions being made about Sarah and her boyfriend's sexual capabilities. A look conveying the thought "Aww... isn't that a shame..." can cut deep.

Surinder relates a memory

... of two carers coming into my home... and one carer's speaking to the other, saying "Does she like this in her food..." and "Does she like that in her food..." ...and I said "Excuse me... I'm here... please speak to me... on my description and my sheet it does say I'm mentally alert, so please speak to me... and not to your colleague... I am here..." (laughs) (1.1:304)

Power relations become especially pronounced in encounters with disability industry professionals. The experience Surinder describes involves being cast in the disabled role as incapable invalid, unable to think or voice an opinion for herself. However, again just like Mr McHenry, these care staff occupy the subject position of non-disabled people while Surinder is positioned in the disabled role. The home carers' opinion of their own worth is directly related to the indignity and lack of value ascribed to Surinder.

As somebody with a hidden impairment and a degenerative condition in its early stages, Hazel is able to escape being placed by others in the disabled role for most of the time, and for this reason seldom thinks of herself as disabled:

I still see myself as being lucky and I don't generally see myself as a disabled person at all... (1.1:189)

It is revealing to discover that the occasions she can recall when she *has* felt disabled are when her competence has been called into question by a non-disabled professional:

The only other time I've ever seen myself as different was to do with getting a repeat prescription for my medication... this nurse was blaming me for sending a fax in when they'd changed the policy about sending faxes, and she was telling me I shouldn't have sent a fax, though there'd been no information, no notices at the surgery or anything, nothing to tell me the policy had changed... I felt different then,

and really peed off... I saw myself as different at this point and... I don't know, what's the word... excluded... that I was different from normal able-bodied people... (1.226ff.)

I would suggest that Hazel, as a professional working within a charity for disabled people, if asked, would struggle to come up with a definition of the social model of disability other than in general terms. Throughout her interview she uses the term 'people living with disabilities' (e.g. 1.1:224), emphasising people's humanity before their 'disabilities', and expresses herself in terms framed by the medical model. Yet in this statement she expresses as clear an understanding of the social model as any expressed in my interviews with disabled activists: *I felt different then, and really peed off... I saw myself as different at this point and... I don't know, what's the word... excluded... that I was different from normal able-bodied people...* What Hazel is expressing here is a sense that being disabled is not an individual condition but an oppressive role.

All they're trying to do is make a connection

Of the sixteen disabled people I interviewed only two described unasked for interest as anything other than unwanted intrusion.

Ash states that:

I've always noticed that people have been very, very helpful in the street... opening doors and that... even people that you wouldnae expect... just to say, like, football supporter people... letting a guy by and that... (1.1.47)

As Paolo Friere has remarked, self-depreciation is a characteristic of the oppressed, deriving from their internalization of the opinion the oppressors hold of them (Friere, 1974:38). To Ash it seems an act of kindness that strangers should take the trouble to notice him and offer help.

As Bourdieu notes:

Resistance can be alienating and submission can be liberating. Such is the paradox of the dominated and there is no way out of it (Bourdieu and Wacquant, 2007:24).

The smiles and kindnesses of all sorts of non-disabled people, even 'football supporter people', can as easily be experienced as expressions of warm fellow feeling as the gestures of members of a relatively powerful social group expressing condescension to members of a

less powerful social group. Indeed, given the nature of ideology it is likely they will be experienced this way. The submission of people with impairments is most often not a deliberate concession to the 'brute force' of non-disabled people, but resides, rather

in the unconscious fit between their habitus and the field they operate in. It is lodged deep inside the socialized body (Bourdieu and Wacquant, 2007:24).

It would be wrong, however, to represent Ash as being entirely comfortable in the disabled role. Some of his statements might suggest this is the case:

...if I didnae become disabled I wouldnae have... met all these people I've met at Bonnybank Centre... and you do realise how grateful... (l.1:231ff.)

Other remarks, however, suggest that at a deeper level he is aware of the fact that he is acting an imposed role:

I did think I had to slot into that wee box of being different... I don't know... some folks don't like to say that, but you were fitting into a box, you were different... I think I'm in a box, I'm definitely in a box, disabled and non-disabled people... (l.1:152ff.)

Anne also offered a more sympathetic view of the intentions of non-disabled people when they unexpectedly intervene in the lives of people with impairments:

I feel quite sorry sometimes for non-disabled people who just don't quite get it right... and all they're trying to do is make a connection... or they are trying to do what they think is right... and all they need is a little education... and I know plenty of people... wheelchair users, for example, where somebody's come along to the car park and they've just put themselves in the car, and they're about to put the chair in behind them... and somebody will come along and stick the chair in the boot for them... you know... trying to be helpful... and that's not a bad person... it's just somebody who... er... might be a bit stupid (laughs)... whatever... you know... (l.1:483ff.)

It might be considered that Anne recognises non-disabled people, too, are involved in playing a role (the non-disabled role) which they no more regard as a role than people with impairments consciously regard being disabled. It is possible to suggest that Anne recognises that non-disabled people are as much actors in a socially constructed reality in which all are

alienated but within which some are more fortunately positioned than others. However, placing this remark alongside others, this seems unlikely:

I don't think it behoves disabled people to judge non-disabled people... er... on the basis of the fact that they're not disabled and therefore can't possibly know and empathise... er... I find that utterly ridiculous... er... because everybody has a life experience... er... of bereavement... divorce... sense of loss... for example... and... you know, these things can affect... kind of... yes, of course they don't know what it's like to be disabled... they don't know what it's like not to hear... why would they... because it hasn't happened to them... but to say they can't empathise with us in a sensible manner is, I think, slightly ridiculous... of course, yes... of course there's plenty of people who'll go "Oh, you poor soul!" (laughs) but that's just until they get to know you for five minutes and then you start speaking to them normally and then they start having a conversation and they forget (l.245ff.)

Anne suggests there is a sense in which the experience of impairment can be likened to bereavement, divorce or loss. She suggests that non-disabled people are able to empathise with disabled people by sensitively relating the experience of impairment to their own negative experiences. Rather than representing a radical understanding of both the disabled and non-disabled subject positions as social roles, Anne's statement re-emphasises a view of impairment as personal tragedy.

People who don't get it

Why can't they see it... they're looking behind it, underneath it, above it... it's right in front and they can't see it... why... (l.1:167f.)

Surinder expresses a sense of exasperation at the fact that so often people in her life who might be expected to understand and be sensitive to her issues and experiences simply get it wrong. They just do not seem to 'get it'. Sarah talks about the ways in which lack of understanding can distort and spoil friendships:

In the past few years I've had some really good friendships that I've just ended because I just felt that it's too much work trying to explain what my disability... cos there were a few people who just sort of like... were nice to me, but I didn't really feel they were nice to me because of me... they were just nice to me because they felt sorry for me... and I just thought I don't want to even go down that road... so it

was a case of I just cut off all ties completely... (l.1:757ff.)

Being befriended out of sympathy is an experience that Sarah rejects for it involves a dependence and humiliation which is felt as demeaning. Equality and mutual respect, attraction and empathy rather than sympathy are necessary characteristics of friendship. With these friends Sarah was cast in the disabled role, playing the part of a grateful cripple who should be thankful that she has friends nice enough to overlook her afflictions. The winners in this relationship were the friends, who were able to feel good about themselves because showing willingness to spend time in Sarah's company demonstrated their own virtue.

Sarah talks about the disempowering impact that these friendships had:

My friends before would be like "Oh, you can't talk like that... because you're with us, and that's embarrassing us..." ... or if the other way it would be like they would overtake... they would... they would get angry on my behalf... I had a big argument with someone about it... I was, like, "Why did you do that..." ...they were, like, "Well, it's always you that's getting angry with them..."...and they felt like they were doing me a favour... I was like "No... just listen... and then tell me... don't try and be my voice... you know... just listen..." (l.1:789ff.).

To be told she cannot speak her mind *because you're with us, and that's embarrassing us* sent Sarah a clear message that friendship was contingent upon staying within the disabled role. It is unlikely her friends saw the contradiction in this relationship, for they appear to have felt a genuine protectiveness towards her. In the situation Sarah describes, a friend intervened on her behalf in what can be imagined to have been a situation of discrimination or harassment. The disabled role here involves being seen as being vulnerable and in need of the protection of others. The work involved in trying to have her own voice respected is experienced by Sarah as tiresome.

Sarah restates this when she remarks:

people my own age don't really understand some of the issues and... and I don't want to have to bring it up all the time... cos it gets kind of tiring to have to explain... (l.1:954ff.)

Her appraisal of why she finds herself situated in such uncomfortable places is perceptive while still remaining bound within disabled role thinking :

Cos we have this idea that everything should be perfect... and that everything should be a certain way... and that if you're not a certain way... then you're not perfect... and it's not right... and because we're told that we have an impairment or something wrong with us, then we automatically feel that we're not perfect... and...I think it can be worse if you're, like, not that I'm saying that people who are all there don't feel it, but I think... (1.1.810ff.)

Sarah recognises that self-identity as flawed or imperfect is the result of being told 'that we have an impairment or something wrong with us', demonstrating an intuitive awareness that the problems she experiences arise not so much from impairment itself as from society's response and reaction to impairment. Yet she also refers to non-disabled people as 'people who are all there', implying an acceptance of the identities of people with impairments as being 'not all there'.

In describing his excitement at having first encountered the social model, Charles recalls that:

at first it was such a head rush... trying to go too fast... I can remember trying to teach my mother the difference between disability and impairment and being angry with her... she still hasn't got it... and she works as a carer... works with disabled children... (1.1:821ff.)

Charles had told me earlier that his mother had drummed into him as a boy the idea that:

"You're not disabled, you're handicapped, because disabled sounds like you're not able to do... You are, so handicapped is better, cos it's like you're disadvantaged, you're handicapped..." (laughs)... (1.1:15ff.)

This was a position that, with some amused embarrassment, Charles admitted to holding until his mid-twenties. He talks about the first time he attended a Disability Equality Training session:

I can remember having an argument, the handicapped argument, and still saying “My mum said...” (laughs) (1.1:622)

The evangelistic zeal Charles felt about the social model is described as ‘a head rush’. Yet the gospel message fell on ears that hear but do not understand, that listen but do not believe. Charles says of his mother that ‘she still hasn’t got it’. The fact that she works as a carer with disabled children compounds Charles’ frustration. The idea that those closest to disabled people might, by virtue of their closeness gain insight into the situation, is further diminished by Charles’ comment that:

My dad did say not so long ago “I don’t know why they went away from ‘spastic’... Everyone knew what it meant...” (laughs...) (1.1:838ff.)

For Roshni, part of the problem of experiencing disability is that people with impairments are compelled to conform to other people’s expectations because, while these are the only expectations voiced, there is perceived to be no other ways of going about things:

people from the (inverted commas) ‘normal’ community will relate to you based on what they understand disability to be... (1.1:800ff.)

Roshni feels that even people who she might hope would know her well do not, because in relating to her they are imposing their own perceptions of impairment and disability, perceptions which reflect a dominant model.

...you think you know me, but you really, really don’t... and I sometimes wonder to what extent people actually do really, really get to know you as a disabled person, because I think that there’s so much beneath the surface that you’re constantly learning... in terms of how you manage yourself, in terms of how you relate to your identity, how self-aware you are... that I think it does have quite a profound impact on the nature of the relationships you form... (1.1:763ff.)

Bodies

Participants frequently raised the issue of sex and relationships in terms of tensions experienced in developing positive identities. There was a strongly expressed sense, particularly among participants who have been disabled from a young age, that this had been

felt (particularly during adolescence) to have been an area of human experience they were excluded from. As Sarah put it:

It's, like, for everyone else, but not for you... like, why? (1.1:1207).

In contemporary British society there appears still to exist a strong taboo around the subject of disabled sexuality. For instance, the Observer Sex Poll 2008 found that:

Seventy per cent of Britons would not consider having sex with someone who had a physical disability... while only four per cent have actually had sex with someone with a physical disability (Guardian.co.uk, 2008:*unpaged*).

It appears that the idea of disabled people having sex or of having sex with disabled people is one that causes considerable public discomfort. There are many reasons around themes of normality, abnormality, aesthetics, eugenics and economics that could be suggested to explain this, but the impact on the identity of people with impairments is to undermine their sense of worth as human beings.

Sarah talks about her experience of having been denied the opportunity to think of herself as a sexual person or to develop a sexual identity. This has been felt both in family settings and among peers. The opportunity for young adults to engage in romantic attachments and to use these in order to experiment and develop emotionally is regarded as a usual part of growing up. Sarah describes being faced with expectations that this is something she will not participate in:

(My gran will) talk to my cousins about stuff that she won't talk to me about, like...the prospect of me having a boyfriend to my gran is just alien... but, erm, my cousins who are the same age as me, that's fine... and it's like I bring it up, and I'm like "Oh, Gran, I've got a boyfriend..." and she's just like, "Ah, yeah, yeah, yeah, he's just a friend..." (1.1:472ff.)

It is as if it is thought that ignoring the emotional and physical feelings of disabled young people will somehow make them go away. Sarah adds further on:

It all comes back to sex, I'm sorry, but there's never any... oh God, here I go...

there's never any representation of disabled people and sex... it's always like "Ooh, you don't do that..." ...kind of thing... which also doesn't help... there, I said it... it's not... it's not so much about sex, it's like... getting back to, like, talking with other young people, it's like... they don't see you that way, so how can you expect to see yourself that way... if you've not... (1.1:1113ff.)

Roshni echoes Sarah:

Girls were becoming aware of boys and vice versa, and there ain't any of that going on... and there's also this subtext within a lot of special schools that if you have a disability, you're not going to be interested in boyfriends, or alcohol, or any of that... basically, it's way out of your league, you know... (1.297ff.)

The expectation that young disabled people will not only never get off with anyone but also not even be interested in getting off with anyone comes across as not just oppressive but as dehumanising. Disability industry professionals can repeat clichés about how important it is to talk about *people with disabilities* but in closing down such areas of experience they impose considerable restrictions on what being a person involves. While there exists much current public discourse on the vulnerability of disabled adults, vulnerability is not an inevitable outcome of impairment, but is an outcome of the social and educational environments and opportunities disabled people have experienced, or have been prevented from experiencing, in their youth (Oliver, 1996).

Roshni points out that while non-disabled teenagers are culturally encouraged to try out their sexuality as part of identity development, for disabled people:

I think that you... you then find, later on, in your adult life you start asking questions about your identity which were perhaps better placed, or would fit better, in your teenage years, but because you had to stifle them, growing up, erm... they take different forms later on...(1.1:1032ff.)

One example of the impact of this prevention of emotional growth can be seen in Kevin's reflection that:

It's never gone away... relating to women... I can talk to older women, but I could never approach a younger girl... or younger woman... it's very, very difficult... you know, I mean... I did get married... although the first girl I married was too young... she was just... she was almost as bad as me, really... she'd never had a

father... I found out in later life that she'd had an abortion before I met her... I guess she was easy... it sounds an awful thing to say, but she was an easy girlfriend to have... so... I guess that's how I managed to get it off with her, if you know what I mean... whatever the expression is... but my second marriage... where I got two daughters... she was an older woman... thirteen years older than me... and... er... she was easier to get along with... so once again, it's... no disrespect, but... erm... she'd also had a bad upbringing and early life... (1.1:596ff.)

The fact that Kevin married twice indicates his need for female contact, love and affection. His lack of confidence in relating to girls or women was a result of his incarceration in special school, during which time he was deprived of ordinary growing experiences. The long-term impact of this deprivation on Kevin's marriages has not been positive:

My wife, she... in regard to doing the business with her... she said that once a week was fine... so in the end I had two daughters... and... erm... as a result of going to this school I wasn't even capable of relating to them... I mean, I didn't really relate to them... you know, I was one of these men who should never have been a father... because we'd led a monasterial life... and I couldn't... erm... I'd never had a relationship with a girl, really... or anything like that... never mixed with girls... and therefore a young girl to me was something I'd never come across... and when I had them on my own... it sort of made me... I didn't like the thoughts I was having... so in the end I said I'm going to have to leave home... I eventually left home... and kept in touch... kept paying the mortgage... we eventually... she said "Oh, I want a divorce" ...we split up... (1.878ff.)

The negative self-image revealed in Kevin's perception that only 'easy' girls were available to him, is also evident in Ash's statement that:

I've only had a few girlfriends... every girlfriend I've had, they've had something wrong, or should I say 'different'... I think I should... they've had mental health or physical... I've never had a girlfriend that's been in a job or been quotes 'normal'... (1.1:951ff.)

The relentless representation of impairment as something 'wrong' with people can eat away at identity, spoiling the way in which the self is experienced, harming the way that disabled

people regard other disabled people, accepting a definition of self as somebody worthless, to be avoided, unattractive, unlovable, abnormal, wrong.

It is not all, however, about sex as physical experience. Sarah emphasises that she is not talking simply about sex in physical terms, but also about the emotional aspects of being involved or feeling excluded from relationships:

The issue isn't always about being physically not able to do something... it's the isolation that goes along with that... I would go out and, like, d'you know... (my friends) would always get attention from people... and you wouldn't... you'd be seen as the one that people would talk to that... do you know what I mean... and it's not to make me out like a slut or anything, like... always wanting to go out and have sex... but it would be nice to feel... you know, that somebody saw you as attractive... (l.1:1009/l.1:1164ff.)

Being the one who is always talked to but never snogged means it is only possible for Sarah to experience herself in terms of the disabled role, as what she is not, rather than as being valued for who she is. A cultural message is hammered home that impairment can only be experienced negatively. Simultaneously, her presence enables her friends to define themselves as being unlike like her.

Charles was frank in his discussion of his own sexual journey. He remembers that by the time he had reached his early twenties

it kind of obsessed me... and because it became the... kind of... goal, it was like all my problems would go away, you know, if I was in a relationship... (l.1:431ff.)

When popular culture endlessly represents active sexuality as the norm or ideal for young adults, knowledge of exclusion from this experience can create a heightened self-perception of abnormality.

In the following statement Charles describes parental prejudice he experienced dating one of his Community Service Volunteers. The fact that this woman met him as a Community Service Volunteer in the first place suggests motives of kindness. However, pressures from her parents put an end to this relationship. Charles then describes what he considers the lengths he was prepared to go to in order to be in with at least the hope of a chance for sex:

But she was a nice woman, and, you know... we went out for a year and even went to Colombia... and I met her parents... and her parents were like “Oh, my God...” ...it was like, really obvious they didn’t want her with someone like that...so then I went out with a woman called Miriam for a few months... who, again, was like... I seem to attract a very religious sort... so I had to pretend to be a Christian just to get my... (laughs)... there was that and the odd snog but no sex... no actual sex... and that became such a big issue... (l.662ff.)

Charles’ feigning being a Christian might have been a useful strategy in terms of pulling, but the lifestyle aspect of Christianity meant that, to his regret, sex was not on the cards.

Outsiders

That Charles’ experiences of such tensions are fairly ordinary for disabled people is verified by the existence of The Outsiders Club. Outsiders is a London club established by Dr Tuppy Owens which, in its website blurb, describes itself as:

a self-help group for people with physical and social disabilities. We offer members the chance to contact others, gain more confidence, make new friends and perhaps find a partner. Problems in forming relationships often result from the way we’ve been treated: parents being over-protective, friends condemning us as ‘not marriage material’, residential staff denying our rights. Unpleasant early experiences often result in continual fears of rejection. Newly disabled people may find it difficult to adapt, and may lose their partners. Many of our members are shy when it comes to flirting. Many come to us depressed and despondently showing little interest in themselves. Outsiders gives a new lease of life (Outsiders, 2009:unpaged).

Charles’ recollection of Outsiders paints a slightly less roseate picture:

I was like twenty-five, twenty-six probably, and still a virgin in that sense... so... and we’re in 1999 now... erm... and I went to Outsiders.... it’s a club in London... and it’s dodgy as hell... so it’s like a sort of club where disabled people go, basically, to get laid... (678ff.)

Nevertheless, Outsiders seemed at least to offer him the promise of finding that elusive experience:

So I was going to that... I went down to a few on weekends... met various people... and, like, Tuppy was saying “We’ll set you up, you’re a good-looking guy... why on

earth haven't you had a shag before..." ...blah, blah, blah... I knew it was, kind of, not a great organisation, but... you know... (laughs)... erm... (l.724ff.)

This promise was soon fulfilled, as Charles recounts:

So I went to, like, one of their fund-raisers... It was in the West End... and it's, like, basically, a striptease night... erm... hosted by Mat Fraser...towards the end, Mat goes "Do any of you dare to come up here?" ...and I was sat next to this woman called Debs who I'd met a couple of times at the club, she was a non-disabled woman and I'm in the wheelchair... next thing I know I'm on stage, stripping this woman... as she strips me... and that was it... and then at the end everyone was going "Aw, yeah, you were brilliant..." so I kind of started seeing Debs for a while, and that's how I lost my virginity... well, that was what led to it... and that gave me so much confidence... (l.1:733ff.)

Lola was the other participant who talked to me about The Outsiders Club. This was in the context of having already developed an identity as somebody who wanted to challenge conformist assumptions around disabled sexuality. However, this identity only emerged in later adolescence and was very closely associated with rebellion against both the stifling conditions at the residential unit and the disabled role in which she was cast. Describing herself in her mid-teens, Lola states that

If people could hear me say this, you know, they would laugh... but I wouldn't mind... I actually became scared of men... (laughs)... which is probably quite interesting psychologically... erm... by the time I was fifteen... sixteen... I didn't... I was two people... I was totally two people in conflict inside myself... you would not believe how I was, I was completely introverted... erm... and I thought that I had... I had no idea how I might ever deal with the outside world... I was terrified of it... I remember, cos this place was a huge, sprawling place... to get from, you know, the unit where we were based to physio... you were taken by porters, and... erm... every day became a nightmare, because, of course, all the porters were men, and I was terrified of that... but it wasn't even that... to do with any sexual fear, it was just a general fear, it was weird, I was scared they were going to talk to me... the irony of being scared of boys and men was that I would fantasise about them at the same time... (l.1.393ff./l.1.510ff.)

The fear of boys and men Lola describes appears to be related in her mind to a fear of the world beyond the confines of the medical unit where she passed her teens. Just as the world

outside seemed large and threatening, a phenomena to which she could not relate, so the segregation she had experienced from males meant that these became identified as strange and beyond her knowledge: dangerous (to be afraid of) but also exciting (to be fantasised about).

A conflict appears to have been experienced by Lola in that:

on the one hand they're saying you won't ever have sex, but on the other hand they're modelling you to have this so-called normal life... (l.1.1331ff.)

Lola recalls an instinctual feeling of the need to reject the disabled role in which she found herself. She appears to have been aware of a contradiction between playing the part of a 'normal' disabled person (compliant with the requirements of the role) and of achieving the things that such a role involved aspiring to:

I think that... I was also aware that... erm... I didn't actually want a so-called normal life... that was probably a very complex mechanism going on in me, because of who I was... or who I was trying to be... which partly was resisting this passive model of disability... which to me was to be living a fake identity, to be living in this fake normality... cos I didn't feel that... again, it was more conflict... cos I didn't feel I wanted to be modelled like some crippled Barbie or whatever, to be shoved out on a conveyor belt, to have 2.3 children with Mr Normal Bloggs... that wasn't... that was never going to be my lot anyway... (l.794ff.)

Lola remembers that:

my early sexual experiences were all with girls... I think, again, that's fairly common... I mean, I realised early on that I didn't have those barriers either, in terms of being... kind of... classifiably heterosexual or... I won't go off at a tangent into that, but I was very aware that I was curious... erm... and... then, by the time I'm fifteen-ish there's all this stuff about discovering masturbation through, erm, girls... like, the older girls... I was very lucky in that way, in that I seemed to click and connect to slightly older girls who took an interest in me... (l.1:514ff.)

One of these older girls, who had joined the medical unit from the world outside, was named Sadie. Lola recollects that:

Sadie used to do amazing things... cos, like, we'd all had hip replacement surgery, and she used to say, "If you keep practicing straddling a chair, you'll be able to have sex..." ... she used to tell us wonderful things like that... who else would tell us... the staff wouldn't...(l.1061ff.)

After a year outside during which she attended the local further education college back home, Lola had what she describes as a nervous breakdown which led to a suicide attempt. When her impairment flared up she found herself again within the medical unit (l.1.1050; l.1.1097). She recalls at this time the arrival onto her ward of a girl named Violet who was to have a major impact on her ideas about sex and identity:

She'd never been to special school... significant... although she'd had arthritis since she was six... but she'd managed... she's twenty, I'm nineteen... so she's been in the real world... very significant, I think... she'd had some very serious issues with her impairment, life-threatening... her version of arthritis was slightly different and tended to make her very ill very quickly... so she was on a long recovery period... but we... erm... that was it... Violet changed my life... absolutely... and I would say we politicised each other... erm... within three months of meeting we'd even changed the way we looked, we shaved our hair, we'd both become very punky... (l.1.1134ff.)

While Lola and Violet soon decided that they wanted to get out of the medical unit and to share a flat together (l.1:1172), this was a process that took four years to achieve (l.1:1218), involving a gradual process of transition, during which they spent less and less time in the medical unit:

That was the other strange thing, because we weren't children any more... it was interesting, then... you're the cast-offs by then, and if their system hasn't worked on you... fuck you, then, kind of thing... (l.1:1223).

Lola first encountered Tuppy Owens and the Outsiders Club around the time she and Violet were sharing a social services 'test flat', being assessed for life skills (l.1:1229). This took place during the late 1970s, during the flourishing of punk rock:

I was really punky looking... erm... and I dressed with much more awareness of my body... to exaggerate it and flaunt it and... I remember Violet shaving the sides of her head off and writing *Fuck off*... that kind of thing... and I had very short, cropped hair and a little baby Mohican... quite a Siouxi Sioux look... and wore a

lot of PVC... you could just imagine it, it was just shocking to the world... shocking to my mum... (1.1:1248ff.)

Talking about the importance of punk in terms of its impact upon her development, Lola says:

Punk revolutionised me, there's no doubt about it, and it was quite a marvellous thing to me... I think if you were into punk you can never not be a punk... (laughs...) in your identity, so... erm... that's another part of the puzzle for me, in that it definitely... and that was... that made me political actually... yeah, anarchy, being able to think of different models of being... to question... that you had a right to break down barriers even, there was a lot of that in punk... obviously to do with class structure and sexism... and to me it just absolutely... and also, just that thing of celebrating in a dark way, of just celebrating... you know... I know it was quite nihilistic at times, but... just that thing of not caring... and even in terms of how I looked by then... cos, of course, punk wasn't exactly about standard beauty, and that was very powerful... (1.830ff.)

Punk's embrace of areas of life rejected by mainstream culture as negative and ugly was something Lola found personally empowering as part of a process of growing more confident about her own body. As David Mitchell and Sharon Snyder note:

The power of transgression always originates at the moment when the derided object embraces its deviance as value. Perversely championing the terms of its own stigmatisation, marginal peoples alarm the dominant culture with a canniness about their own subjugation (Mitchell and Snyder, 2000:35).

It was as a punk, then, that Lola first became involved with the Outsiders Club.

Tuppy really had no understanding of how naïve someone like me might be... from my very limited life experience... say I've hit twenty one, twenty two... I've had very few sexual experiences... Tuppy thinks I'm this wowee sexual adventurer... how stupid can you be, basically, I think... that's one of the big issues, I think, with her... no understanding of anyone's past or... positioning in society, in a sense... and what is oppressing you and defining you...

Lola recalls that she was regarded by Tuppy as ‘like this little chicky, waiting to be plucked’ (l.1:1377):

I suddenly was immersed into this... Tuppy would have this... “Oh, let’s go on a gang bang party in Luton...” ...she was not a safe person to be with, and I probably escaped quite well... I was taken to all kinds of strange houses and... I had some very nasty experiences in Outsiders... but I did have some good ones, I have to say... and it did... in some way, even the bad ones, looking back, were... probably weren’t that out of the ordinary... but I... I... like... it was almost like I had them in very concentrated form... erm... (l.1:1356ff./ l.1:1375ff.)

It is, I think, possible from the above to identify tensions experienced by Lola in regard to sex and sexuality. In her statement *I had some very nasty experiences in Outsiders... but I did have some good ones, I have to say...* there are echoes of Charles’ *I knew it was, kind of, not a great organisation but... you know...* Centrally the issue is to do with the possibly dangerous positions into which Lola was prepared to put herself, having become involved with Outsiders. The years she had spent in an isolated medical unit in the countryside had had a devastating impact on opportunities for ordinary experimentation and development. While staff within the unit may have been insistent in telling the girls there they would never have sex (l.1.1331) this did not mean that the girls’ sexual drives therefore became subdued. The contrast between the role expectations held about her by the unit staff and the types she met in Outsiders is nowhere better illustrated than in her comment that:

There were issues with the Devotees... fetishists for disability... particularly focussed on people who... on amputees... I think twenty odd years ago it was much darker, because the whole thing... you know, fetishism was darker, anyway... and you’d get guys ringing you up and saying “Can I come over your scars?”... when you’ve come through this medical unit where they’ve made you... then you think that any man who says something sexual to you wants to marry you... well, someone saying can I come over your scars is the freakiest thing in your life... (l.1:1289ff; l.1:1321ff.)

Closeness

To surmount the situation of oppression, men must first critically recognise its causes, so that through transforming action they can create a new situation – one which makes possible the pursuit of a fuller humanity (Friere, 1974:24).

Within a culture which represents disability as individual tragedy it is easy for the impaired individual to experience disability as something personally wrong. There may exist a sense of having been treated unfairly or of having been dealt an unjust hand in life, and a vague notion that for things to change there will need to be an improvement in attitudes, but beyond that there lies a lack of clarity about how this is to be brought about. Ash suggests that to his way of thinking positive changes occur as a result of a natural social progress:

I feel it's getting better all the time... there's some words which shouldnae be said, some horrible words that are... but the thing is they're no said as much... like the word you use for Down's Syndrome... they're no said as much as they were when I was younger, so that's like a step forward... kind of respect... people are respecting more people that are disabled, and... in fact, maybe in the 70s, horrible things were said, horrible words, and... I think it's just a natural progression that things move on...that things move on... and people become more accepting... (1.1:174ff.)

In the meantime, Ash accepts his place in life as belonging with other disabled people:

The majority of my friends are mentally ill or physically disabled... I keep with my people... they keep with their people... it's probably just the way it goes... it's to do with day centres, and... you know, I go to a day centre for... and I do think it's good... lumbering's no the right word... I do think it's good keeping all the disabled people together... (1.2:23ff.)

We can recognize in Ash's statement the effects of disciplinary power. He has learned to want what he has been told it is in his interests to want.

Discipline systematically works to emphasise its effective and benign productivity while disguising its repression, so a disciplined social formation or a disciplined body is one that complies with the system which controls it because it has been persuaded that its benefits are greater than its costs, that what it includes is better than what is excluded (Fiske, 1993:17).

There is no doubt that Ash gets much from attending Bonnybank Day Centre, including many friendships:

when I go to my centre at Bonnybank I mix with a chap... I play Scrabble with him

weekly... I get on really fine with this chap... and he was a prison warden...he took a stroke... but he was retired before then...I'm almost pushed into mixing because of the centres I go to... like with mental health... like, this is how... I mix with people with mental health and people with physical disabilities... (1.1:752ff.)

For somebody as susceptible to depression as Ash, being situated in an environment where interaction is required is experienced as a good thing. He values Bonnybank Centre as a place where his identity is confirmed:

You want to have somebody there to say "Oh, I had a sore leg today," and they'll say "Oh, my leg was sore too..." (1.1:674)

This identity, however, is not one which involves questioning existing social arrangements. Scrabble is more popular in day centres than conscientisation.

Rose also speaks of the importance of talking with other disabled people. In the following passage she recounts the part that mixing with disabled people had in her own acceptance of being disabled:

I went on holiday with a disabled group, er... and I thought "Rose, grab the bull by the horns... go and see what it's like... it can only be... you know... it can only be bad..."... and I think that would have been in about 1990... early 1990s... 91... 92...and... I went off alone, with a scooter in tow on the back of a car... and I'd had to borrow everything... I borrowed equipment, to try it out... and I met all these people... and at that stage, it was... "I'm Rose... they're disabled... I'm going to meet them..." and by the time those few days with them were over... that's when I thought "They're just the same as me..." ...they've got exactly the same concerns, likes and dislikes, needs and whatever... and I think that is when... that is when I fully embraced the idea of being disabled... because I wasn't afraid of it any more... (1.1:419ff.)

It is likely that Rose's fear of 'the idea of being disabled' involved, to a large extent, fear of the role that disability involves. As Sheldon Stryker notes, roles, as 'relatively stable, morphological components of social structure' (Stryker, 2002:54), carry shared behavioural expectations:

Persons who act in the context of organised patterns of behaviour, i.e., in the context of social structure, name one another in the sense of recognising one another as occupants of positions. When they name one another they invoke expectations with regard to each other's behaviour (Stryker, 2002:54).

Before she knew them, Rose regarded disabled people as alien. It was only through contact that she addressed her own fear of being disabled. Rose's discovery that, actually, disabled people were just the same as her provides another illustration of disability as role. It was the word 'disabled', and the expectations conveyed in that word, that she feared rather than disabled people, who turned out to be rather ordinary. Rose continues by describing her feelings towards other disabled people now:

Er... huge warmth... huge appreciation... and a real sense of relief at being understood and understanding without having to go through all the preliminary explanations, all that sort of thing... that, although we have very different disabilities and very different means, nobody questions you... nobody says, when you say "I can't use that toilet..." (laughs...) or "I can't get into that shop..." or "I can stand, but I can't walk..." or what have you, they just accept it... because they know that you're saying what is fact... not some elaborate story that has to... that you have to be proved wrong in saying... and I've got great friends with different disabilities... some of them working, some of them not... some of them doing this, some doing that, and I... couldn't manage without them... (1.1:770)

In talking of her relationship with her partner Hugh, Jennie says:

we felt we always connected on that wavelength anyway... he's always felt that since getting ill he finds that he can talk properly with other people who have been seriously ill... erm... there's none of this sort of feeling that you can't talk about certain things for fear that you'll offend somebody's sensibilities, or shock them... there's none of the feeling that you always have to be protective of other people whilst getting on with your own business... while getting on with the business of being yourself... people are a bit more realistic about the world being not a very nice place all the time (laughs)... and that means, also, that you don't have to pretend that the world is a terrible place all the time... people who have been through these

situations together... erm... can share humour... there's certainly a lot of humour that goes around cancer wards... (l.1:592ff.)

Jennie describes here the benefits of being able to share with people who have had similar life experiences. Importantly, this involves a realism which breaks through the myth of normality and the ideological position that health is the normal human condition (Frank, 1997).

Sarah talked about the importance in her life of having met and talked with Robert, a disabled comedian who also has cerebral palsy, who she became friends with after seeing him perform at the Edinburgh Fringe:

I hadn't met anyone, like, older than me who was... do you know... that confident and that sure, and kind of... not looked after me, but said it's all right to feel that way... and, I mean, I just felt that... I don't know if it was just, like... you know, I'd never really had in-depth conversations about disability or anything, but just knowing that someone had gone through similar stuff... and was all right... and I suppose, as well, like, it sounds silly, but being quite impressionable at the age I was when I met him, he was married and had a kid and that was something I think I felt wasn't... again going back to expectations... wasn't expected of me... and so meeting someone who had that was kind of like... you can achieve that... and that's what I'd wanted my whole life... was someone to... to look up to... and sort of think you could... aspire to that... for me that was really important... because... well, because of the age I was at... being a teenager, and wanting to have a relationship, and not... not being able to at that point... not feeling I knew anyone well enough... and it was that... I suppose that's when I started to change... to think that, you know, it's all right to kind of feel that way... (l.1:823ff.)

Sarah describes a situation in which, until she talked with Robert, she had been given few indications that she might one day be able to enjoy sex, get married, have children, live an ordinary life. Not only was this something she had felt 'wasn't expected of me', it was something she had felt unable to talk to anyone about. Meeting somebody older than her who, in her eyes, had 'made it' in these terms, was very important for Sarah. While Sarah says that this is what she had wanted her whole life, 'somebody to... look up to', this is about more than saying that disabled young people need role models. Sarah's words are an

indictment of a culture and educational system which offer disabled young people few opportunities to identify themselves as fully human beings. If we consider Sarah 'lucky' to have developed this friendship, to have found somebody she was able to talk with, then we accept that this is not the usual case for most disabled young people.

While the accounts of Ash, Rose, Jennie and Sarah above highlight the value felt by disabled people in having other disabled people to relate to, none of these in themselves offer insight into ways in which the situation of oppression may be surmounted. The accounts considered here so far may even suggest the collective involvement of disabled people in self-oppression. If acceptance of disability identity means acceptance of the disabled role then talking with other disabled people in similar situations, while comforting, does not produce transformative action. There may be felt an instinctive sense of injustice, but also expressed is a lack of knowledge of how to respond to this injustice other than by living with it. If responses that are not critically transformative give assent to existing structural relations, even if they are ironic or knowing, they are complicit in preserving existing structures of domination.

Power

Mary talked about her experiences after starting work as an access auditor for an organisation of disabled people in West Yorkshire in the early 1990s:

Just interacting with other disabled people in a more kind of radical environment made a difference... and... you know... well, I did kind of mention that I'd been to special school... but I wasn't really disabled... at which people just burst out laughing, of course... oh, yeah, Mary, right... and then I went to a conference at the university and... which was around how to make education more accessible for disabled people... and I listened to Tarquin... who became a close friend... and he spoke about the social model... I mean, I'd heard about the social model... but not in the depth that Tarquin actually described it... and for me, you see, it wasn't just a matter of accepting this... it was more sort of an active embracing... of the concept of being a person with an impairment... and moving from that level of political consciousness to thinking well, you're not... you know... you're not a person *with* a disability... disability is something that's actively done to you... so it was at that point, actually listening to Tarquin... I was on the road to being quite radicalised, anyway, but he was the kind of... (l.1.377ff.)

In gaining an understanding of the social model Mary became able to critically recognise her own experience as having involved oppression and to understand the causes of that oppression. She had, up till this point, accepted uncritically her experience of having been segregated as a child and of the denial of the validity of her own experience. Even as she started work as an access auditor she still protested that she was not really disabled. While she focused on the barriers which exclude disabled people, she still considered disability a discreditable personal characteristic. Gaining an understanding of disability as oppression meant that Mary became able to accept herself as somebody with an impairment. Viewing her own situation in a new light transforms her self-perception and her response to her situation, so that through transformative action she is able to pursue her right to be valued as who she is rather than for what she aspires to be.

Mary's politicisation as a disabled person emerged as a result of talking with other disabled people, but Charles points out that it does not necessarily have to happen this way:

In my case it was talking to politicised people who actually weren't disabled... but probably had a much better understanding... of... certainly of the social model than the disabled people I knew... later on, I encountered politicised disabled people, yeah, but... I mean, I suppose that's not what you normally find, really... (1.1023ff.)

Charles makes the point here that what is important is not so much talking with disabled people as with people who get what the social model is about. In his own experience his political awakening as a disabled person occurred through talking with non-disabled allies working within the social model. He goes further, too, arguing that many disabled people still oppressed by the individual model have, in his opinion, little to say that is of value:

I suppose I've talked to a lot of disabled people who weren't politicised who talk shit... (1.1.1018)

Charles contends that it is not enough, or at least not necessary, to be disabled in order to argue progressively:

And I think what the difference is whether you're working to the social model or not...rather than... you know... whether or not they were disabled... (1.1:1042ff.)

Ben recalls his own involvement in the disabled people's movement during the 1980s:

Most of the time I just related to people at a political level... being involved in a

political struggle with them, they were either for the same things as I was or they were against it... so it was like a discourse going on there, a discourse around disability but not particularly talking about... your own self... it was trying to look at pan-disabled issues... erm... at the time and looking at... erm... confluences rather than conflicts... and building, erm... people were coming together in coalitions, councils of disabled people about that time, so it was bringing together... erm... a lot of different groups who didn't necessarily get on easily, people who'd campaigned on their own, sort of isolated spheres until then... who were coming to take on other people's issues and understand that they're all part of the same thing... it wasn't just an individual thing about... well, I need a ramp to get into that building... erm... it was about other people's access rights as well... and the whole way in which legislation and everything wasn't there... to ensure these rights... (1.1:397ff.)

Ben describes being part of what was sensed as a movement involving overt political struggle. This involved forging a new sense of disability identity among groups of people with different impairments who had previously not seen any connection with each other and had viewed their interests as disparate. This politics seemed new and challenging because, while many disabled people had previously actively avoided association, the coming together and collective engagement between different groups working within the social model seemed to suggest the possibility of bringing about real and decisive social change.

Mary speaks of activism in the disabled people's movement in the 1990s as involving a sense of being part of something larger than herself:

when we went to block Telethon... when we went to protest outside *Children in Need*... when we had DAN actions at Leeds Station and stuff like that... handcuffed ourselves to buses and trains and stuff like that... we certainly... the people I was with... believed ourselves part of a movement... certainly when we had the big demonstration in Edinburgh... when we blocked off the Canongate... we certainly thought we were doing the same sort of things people had done fairly recently in Nottingham or in London... we felt that we were part of this much larger group... (1.1:568ff.)

It is this sense Mary describes being part of a larger collective which enabled her development of a strong disabled identity. While Ben and Mary are both in their early fifties,

however, their descriptions of having been involved as part of the disabled people's movement are quite different from Sarah's, speaking as a young disabled woman in her early twenties:

I know of it... and would consider myself to be part of it... but not in the same, like... not... not as in disabled people... it's more about... like, including every one, rather than saying we're a different group... and we want the same... but it's, like, now... now it's just about accepting every one... regardless... but I don't think that's necessarily working... (l.1:1025ff.)

Mike Oliver and Colin Barnes have suggested recently that:

we no longer have a strong and powerful disabled people's movement and the struggle to improve disabled people's life chances has taken a step backwards (Oliver and Barnes, 2006:unpaged).

It was a mistake, they argue, for the movement to have become too focussed on the single issue of securing anti-discrimination legislation. With the passing of the Disability Discrimination Act 1995 (DDA), a piece of legislation the disabled people's movement had major reservations about (Swain, French and Cameron, 2003), much of the momentum went out of the movement. While the British Council of Organisations of Disabled People refused to participate in the task force set up to oversee its implementation, the large disability charities run by non-disabled people 'fell over themselves to nominate members' (Oliver and Barnes, 2006:unpaged). As Oliver and Barnes further observe:

Since the late 1990s the combination of Government and the big charities have successfully adopted the big ideas of the disabled people's movement, usurped its language, and undertaken further initiatives which promise much yet deliver little (Oliver and Barnes, 2006:unpaged).

While talk of disabled people's rights is increasingly heard from the charities, Oliver and Barnes argue this is empty rhetoric:

Our history has taught us that in the recent past these organisations played a leading role in keeping us oppressed and out of society. Name changes, tidying up their language and employing token disabled people cannot disguise the underlying reality that these agencies are interested primarily in self-preservation and that they

will say and do anything that is politically expedient in order to retain their influence in Government circles (Oliver and Barnes, 2006:unpaged).

Sarah's experience is that the disabled people's movement she knows emphasises diversity above particularity. Answering a question about whether she feels there is an active political disabled people's movement out there for her, she replied:

I don't feel that... and I speak as someone who's quite involved, doing loads of stuff for people with disabilities... but I don't feel it's the same... like... we're calming it down more than anything else, really... (l.1.1040ff.)

On further questioning, it becomes evident that when Sarah talks of the disabled people's movement she has in mind Crackerjack, a local organisation she is involved in which was established in the late 1990s by parents of disabled children:

I'm thinking of, like, Crackerjack when I say that... even in the ten years that they've been running, that organisation's changed... from what it was trying... set up to do... you know, they set out... at the start it was very specific to young people with disabilities and access to leisure and play... now it's changed to citizenship... (l.1.1051ff.)

Whereas Mary was involved in protests by disabled people against *Children in Need*, Crackerjack displays a *Children in Need* logo on its website. Whereas at the Direct Action Network actions attended by Mary disabled people handcuffed themselves to buses and trains and wore T-shirts bearing political slogans such as *Piss On Pity* and *Disability Pride*, Crackerjack's strapline is *Look at the Person*. There is an important distinction between the disabled people's movement and the disability movement. Mary makes the point that charities established by parents and carers and largely staffed by non-disabled professionals are part of 'the disability movement, not the disabled people's movement' (l.1.592).

Sarah identifies as a person 'with a disability'. Speaking as a disabled woman who has reached adulthood some fifteen years after the height of the disabled people's movement, it seems that the analysis which would make it possible for her to name herself a disabled person with pride is unfamiliar to her.

Disciplinary Techniques

I have recently discussed the way in which, in spite of access improvements to public places, accounts by disabled people suggest that

more often than not they are met with patronising tolerance rather than with respectful acknowledgement as equals (Cameron, 2009:391).

While it cannot be denied that many access improvements to public environments have been made during the first decade of the 21st Century, my suggestion is that the role played by disabled people within society remains relatively unchanged. Greater visibility of people with impairments does not necessarily signify greater equality so much as the refinement of disciplinary techniques within disabling society. This will be the central argument of my next chapter, on media representation of disability.

As I was nearing the conclusion of my first draft of this chapter in autumn 2009, the Disability Arts singer Karen Sheader emailed me recordings of two of her recent songs. In 'That's the way' (Sheader, 2008). Sheader sings frankly of a number of disabled characters who, no matter how hard they have tried to be or do what other people require of them, keep finding doors shut in their faces. Embarrassed apologies are made about why they are considered not good enough. In her chorus she sings:

That's the way it is for some people
Some of us were fashioned that way
That's the way it is for some people
Some people keep turning away

Sheader's song 'Oblivion' (Sheader, 2008) echoes Oliver and Barnes above. The language of the disabled people's movement has been incorporated within contemporary social discourse but in a way that offers little prospect for real change:

People say we have lost our language
Stolen from us by a greater force
How could we have made it turn out different
How could we have steered a different course

Sheader expresses frustration at the fact that dominant culture always dominates. While the language of rights for disabled people which originated in the disabled people's movement has been taken up by the charities and professions, repackaged services for people with impairments remain rooted within the same assumptions. This is brilliantly illustrated in a recent story in *The Scotsman* newspaper:

Blind charity aims to raise awareness of visual impairment with tour

Instead of open-top buses and perfectly-poised binoculars, the only aide on the latest Edinburgh tour is a pair of dark glasses. The pilot, launched by the Royal National Institute of Blind People (RNIB), is aimed at making those who take the tour realise what it is like to move around one of Europe's most picturesque cities as a visually-impaired person... RNIB's inclusive society group director, Fazilet Hadi, said: "We are asking the general public to consider what they would lose from their lives if they lost their sight... The tours, launching next month, will be a really powerful way for people to experience first hand just how much losing your sight can impact upon your life." As well as raising awareness of the impact of sight loss on everyday life, the RNIB hopes to boost its profile (The Scotsman, 2009:unpaged).

While the Royal National Institute for Blind People has made much of its name change in 2007 from the Royal National Institute for the Blind (RNIB, 2009:unpaged), disabled people's organisations have rejected the value of simulation exercises for the past two decades:

Simulation exercises, by their very nature, focus on supposed difficulties, problems, inadequacies and inabilities of disabled people. They contribute to rather than challenge damaging stereotypes (Swain and Lawrence, 1994).

Conclusion

I mean, I often wondered what it would be like to be non-disabled... and I suppose wished that I wasn't... but then, looking back, you're wishing not to be... the way that you're being treated.....that's what's at the heart of it... (l.1:255ff.)

Charles' words present us with two ways of responding to the experience of impairment and disability. Charles recalls spending time during his adolescence measuring himself unfavourably as a *spastic* against a standard or ideal of normality. While the subject position of people with impairments is always invalidated, the subject position of the non-disabled appears an enviable one. While much cultural work is done to ensure disability remains identified as an individual condition, the disabled self experiences itself as flawed. Without the social model, disability can only be understood as discreditable.

Returning to Schutz' description of imposed and intrinsic relevances, a rejection of disabled identity by an impaired person involves an attempt at distancing himself from the imposed relevances by which his life is circumscribed. While this may be an understandable response

to negative subject positioning, within the terms of my argument I would suggest it is naive. Charles' description of time spent wondering what it would be like to be non-disabled and wishing that he was not disabled is a description of a confusion of self with the subject position occupied by the self. Ironically, though, and as we have seen elsewhere, as long as he rejected disability identity Charles fulfilled the requirements of the disabled role.

Having since embraced a disabled identity, Charles is able to re-evaluate his earlier thinking. He now recognises the negativity he felt towards himself as the outcome of the personal and social education he had been subjected to. As he says, 'the way that you're being treated... that's what's at the heart of it' (1.1:261). Charles has transformed imposed relevances into intrinsic relevances. He has named the relationship that oppresses him, and in doing so has claimed power. The barriers he has experienced, as well as his formal training in self-rejection, come from outside and have their roots elsewhere rather than within himself.

Had Charles been one among a hundred thousand people with impairments who experienced discrimination, it might have been possible to argue that his troubles were personal, and were to do with who he is as an individual. But because this can be demonstrated as a patterned experience, described by many disabled people, he is able to understand his situation otherwise. In taking on a disabled identity, in identifying as somebody who is disabled by society, he is able to relate in a different way to the tensions he experiences in common with other disabled people. He is able to recognise that these are to be resolved through collective action.

C. Wright Mills has argued that people:

do not usually define the troubles they endure in terms of historical change and institutional contradiction... They cannot cope with their personal troubles in such ways as to control the structural transformations that usually lie behind them (Wright Mills, 1967:2).

I suggest this also is the situation of those who deny disability identity. Seen from the perspective of the disabled individual, it is easy to imagine the troubles they experience as being related to their own physicality; especially when professionals, carers, and media discourse constantly reiterate this perspective. Institutional contradictions appear just too large to address, and besides, this would require engagement with politics (with which people are either disillusioned or uninterested).

Wright Mills describes the sociological imagination as enabling its possessor to understand:

the larger historical scene in terms of its meaning for the inner life and the external career of a variety of individuals. It enables him to take into account how individuals, in the welter of their daily experience, often become falsely conscious of their social positions... The first fruits of this imagination... is the idea that the individual can understand his own experience and gauge his own fate only by locating himself within his period, that he can know his own chances in life only by becoming aware of those of all individuals in his circumstances (Wright Mills, 1967:5).

The same point can be made in relation to the social model of disability. I contend that there is much to be gained by identifying as disabled if this involves transforming imposed relevances into intrinsic relevances in order that these can be addressed. Involved here is a process Friere has described in terms of agents singling out elements from their 'background awareness' and reflecting upon these, making them objects of consideration and objects of action and cognition (Friere, 1974:56). This requires an altered subjectivity and a naming of disability as oppression. It requires a conscious acknowledgement of the processes by which people with impairments are interpellated as disabled and a conscious decision to adopt a subversive stance towards these.

While Wright Mills' sociological imagination and the social model of disability are essential tools for allowing individuals and, specifically, disabled individuals to contextualise their experiences as players on a historical and social stage, I suggest there is a need for other tools too which allow individuals to address and make sense of experience within the detailed minutiae of everyday life.

For what can be recognised as justifiable reasons of positioning, the disabled people's movement has tended to emphasise the structural barriers experienced by disabled people and to avoid reference to the experience of impairment. As Mike Oliver has pointed out, the social model 'is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability' (Oliver, 1996:38). The focus of the movement has been on addressing issues that can be changed rather than those which cannot or those parts of human experience which need not.

In my opening chapter I stated my belief that, while discussion of impairment has not been a focus of the disabled people's movement, this does not indicate a shortcoming of the social model. Nevertheless, while the movement has had its reasons for downplaying the

significance of impairment, this has sometimes been subjectively experienced as causing anxiety. As Brian says:

...at that time, in the mid-90s, there was very much an over-arching sense in which individuals' personal difficulties in living with impairment issues was very much... if you talked about your experience in terms... of... erm...in terms of suffering... in terms of something that wasn't imposed from without...then you were pretty much... erm... you could expect to get kind of quite a short shrift from within the disability movement... and I think, you know, the questions are very, very complex...(l.1:334ff.)

Brian's words express a claim made by disabled people who would criticise the social model (Oliver, 2004). A need is felt to be able to talk openly about impairment and impairment effects as these are experienced by individuals in everyday life without giving credence to the medical model.

The affirmative model I proposed in the previous chapter names impairment as a characteristic of difference, divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society. It creates a space in which impairment can be owned as something that can be experienced positively, negatively, or both at different times, and which can sometimes involve the darkness that pain brings, yet is at the same time to be valued. This is a position which problematises the utilitarian distinction between pleasure (or *good*, or *convenience*, or *advantage*, *benefit*, *happiness*, and so forth) and pain (or *evil*, or *inconvenience*, or *disadvantage*, or *loss*, or *unhappiness*, and so forth) (Bentham, 1987:89). Within such a schema, underlying contemporary assumptions about disability, pain can only be regarded as something deserving pity, disapproval and avoidance.

Rod Michalko suggests that impairment is indicative of the fragility of the human body and subversive in its power to indicate the fragility of the body politic:

The disruption of contemporary hegemonic ideas of reason over passion and mind over body is perhaps disability's greatest possibility. Disability disrupts society's carefully structured and multilayered façade behind which it hides the human body together with its fragility and vicissitudes (Michalko, 2002:166).

The affirmative model establishes the rights of people with impairments to feel okay about themselves and to take pride in who they are even when they are having crap days, and to be able to have crap days as well as great days or ordinary days without having to pretend

otherwise. It also establishes their rights to have great days and ordinary days as well as crap days, to enjoy being who they are as people with impairments rather than regarding impairment as a cloud overshadowing every aspect of their existence. It demands a recognition of impairment as an ordinary rather than an extraordinary characteristic of human experience, and for inclusion within ordinary life on that basis. For me this is succinctly summed up by Sarah P., a woman who has posted a comment on an interview about my research on the website *Disability Arts Online*:

This reminds me how important it is to not apologizing for who you are in any way (Hambrook, 2009: unpagged)

This affirmative model identifies disability as a productive as well as a restrictive relationship. In identifying disability as a personal and social role, it involves a recognition of the kind of actors people with impairments are required to become. Whether this involves passive dependency or triumph over tragedy, either way negates the lived experience of impairment and signifies the desirability of normality.

I don't blame the person, I think it's just all about self-awareness... it's all about the individual... how you deal with yourself first... you know, it's all about looking at yourself... most of it is about looking at yourself... (l.1:448)

Surinder's words return me to the argument I made at the beginning of my literature search. Disability is a thoroughly exploitative relationship because simultaneously it disadvantages people with impairments and those considered non-impaired. Just as being a disabled person involves acting out an imposed role so does being a non-disabled person. While to an extent, in Markell's terms, non-disabled people are insulated from having to address their own temporality, this is distraction which avoids the necessity of facing personal existential questions. The interests of the dominant social classes have no need of grounded human beings but only of consumers. In Richard Schmitt's words, 'the market economy advances alienation by pushing us towards conformity' (Schmitt, 2003:107).

Surinder recalls herself before her diagnosis with MS as having been shallow in comparison with the person she is now:

I think as me as a non-disabled person in the past, no I wasn't happy... I wasn't happy... but then, I didn't know myself then... and didn't have that awareness that I have now... (l.1:795ff.)

As someone with adult experience of being both non-disabled and disabled, Surinder refutes the assumption that impairment is to be pitied. Her words expose the ideological function of the disabled role as myth. Her own experience as a non-disabled woman was preoccupied with what she now considers to have been the mundane trappings of normality:

I can't say for sure cos I don't have the evidence, but I suspect that if I didn't have a disability I wouldn't have gone through all these experiences which have made me the strong personality that I am today... (l.1:831ff.)

Herbert Read commented that:

The whole of our capitalist culture is one immense veneer: a surface refinement hiding the cheapness and shoddiness at the heart of things (Read, 2002:29).

Being positioned on the margins can provide an opportunity to gaze and reflect critically on the mainstream. It can afford an opportunity to perceive things about the world that others miss. While the interests of the dominant classes have no requirement for people who think too deeply, my hope is that the affirmative model will be used as a tool for the development of a critical self-awareness which will become a spur to transformative action.

Chapter 6: Media Representations

Introduction

In carrying out unstructured interviews on media representations of disability I aimed to create opportunity to allow each of the research participants to shape the form and content of our conversations. I did not have a stock opening question but got the interviews underway with invitations along the following lines:

...we're here to talk about media representations of disability and disabled people... and, I suppose, the way you perceive these representations impacting upon everyday life... whether your everyday life or other people's... (Charles, 1.2:09ff.)

My aim was to find out about participants' perceptions of and responses to media narratives around disability in order to reflect on these as resources used by disabled people in identity construction. I also aimed to discover whether participants regarded media representations of impairment as invariably portraying disability as personal tragedy, materialising an individual model of disability. Where the conversations led was very much down to the way each person being interviewed approached the subject, and I was pleased to find that participants responded in various ways. While most interviews took the form of straightforward discussions, some people wanted to talk solely as consumers while others wanted to talk about their own experiences of engagement in media production. While the majority of conversations focussed on TV some people also talked about radio, print media and the internet. Charles had prepared a series of video clips which he played on his laptop and our discussion was directed at these. Surinder produced a number of newspaper stories and images about her involvement with the MS Society and our talk centred on these.

Horizons

Drawing on the phenomenology of Edmund Husserl, Tony Wilson uses the term *horizons* to describe:

frameworks of cognitive knowledge underlying perceptual experience, allowing aspects of that experience to be recognised and identified as instances of types already encountered (Wilson, 2005:16).

Horizons of experience are always learned culturally and intersubjectively and validate established ways of recognising and relating to things and people. They are fixed, Wilson

argues, by the repetitive, structured patterns experienced by individuals within everyday life, through having their gaze constantly directed and focussed upon objects already known or experienced (even if only generally) so that the individual's look is always at what is to some extent already familiar. It is unnecessary with each new perception of an object to re-learn what that object specifically is, for it is recognised as belonging to a type already partially known. If it becomes important its details will come into focus later on. The familiar natures of objects and relations perceived within emerging everyday experience enable anticipation of what things are *like*. As Wilson notes:

as they thus constitute the familiarity of a life-world, horizons allow a cultural knowledge to be used and (apparently) confirmed. (Wilson, 2005:17).

Individuals inhabit everyday life-worlds of pre-given familiarities, assumptions and perceptions as the spheres of taken-for-granted, common sense knowledge. Things are regarded as being the way they are because, apparently, that is the way they just are. Because life-worlds are encountered 'naturally' their character is experienced unreflectively and uncritically. In the quotidian, nature and culture appear as indistinguishable (Bauman, 2001). The life-world is where physical bodies turn into cultural objects 'as people whose physical movements are then meaningful acts, gestures and communication' (Husserl, quoted in Wilson, 2005:17). It involves the embodiment of the subject within a structure of expectations, roles, routines and behaviours perceived as unproblematic and made unremarkable by familiarity. The life-world exists within horizons which mark out familiar assumptions as obvious in that they:

provide the basis (and limits) of justifications in verbal discourse which refer to this level of the seemingly unproblematic... These are significant limits, since cognitive horizons of understanding implied by speech, writing and vision are... inflected by ideology (Wilson, 2005:18).

Wilson suggests that broadcast media, and particularly TV, resist innovation by offering audiences unending opportunities to recognise the familiar. TV re-presents to its intended viewers 'their horizons of experience, their role-based needs, desires and their perceptions of what is rational' (Wilson, 2005:21). It draws on and maintains a set of cognitive horizons of understanding within existing life-worlds, constructing its on-screen artefacts as 'a well-known presence within the viewer's life-world through frequent repetition of form, character and content' (Wilson, 2005:20). He argues that programmes such as talk shows, current affairs discussions and the news:

address their viewers as an extended group of acquaintances, if not old friends... creating a sense of shared participation in events by friends who both know one another and what there is to know (Wilson, 2005:20).

Whether viewers are addressed as acquaintances, friends or as members of a mythical extended national 'family', there is an appearance of an attempt to engage with individuals.

To suggest this, however, is not to imply that the meaning of texts is apprehended and received in the same way by all viewers. As Wilson expresses it, reading is 'always and everywhere a fusion of horizons, drawing upon, and producing difference' (Wilson, 2005:21). Just as any individual's experience is of a series of related life-worlds and social roles (e.g. husband, father, step-father, employee, club member, neighbour, disabled or non-disabled person), simultaneously within the same physical space and yet within a loose cultural community, so appropriation of the meaning of broadcast communication is open to endless interpretation.

It is unnecessary for the viewer to see the same thing as the person sitting next to her, or to recognise herself in the texts of television, so long as she recognises somebody *like* herself or whose roles she can identify with. Viewers will regard texts as they relate to their own experiences and life-worlds, which will themselves be determined by the social roles they occupy in the private sphere of everyday life (which will be dealt with and managed distinctly by particular individuals). While conflicting interests are present in every situation, the meaning of any text can be disputed and challenged endlessly from any number of positions. It needs to be recognised, however, that conversation forms the basis for the establishment of shared understandings, life-worlds and horizons, and that media texts are frequently drawn on as resources in developing these conversations.

The viewer can 'read' the roles which he or she inhabits in particular ways, inflecting them through an individual experience and understanding of the world. The concept of 'role' allows a theorising of the relationship between subject and society which suggests neither a determination of behaviour by social structure nor a reducing of the societal to the individual (Wilson, 2005:31)

While TV, then, does not actually address individuals but social roles within life-worlds filled by unknown viewers, the familiarity implied in the presenter's friendly greeting or smile persuades individuals they are being addressed personally. Karen Dill suggests that:

psychologically speaking, this feeling of having relationships with media figures actually makes some sense. As biological organisms, we weren't designed for this paradoxical social situation where we feel that somehow we get to know people personally from afar (Dill, 2009:53).

Social issues are reduced to the level of the mundane, structural issues are presented as having their resolution within the domestic sphere. Viewers are addressed as a nation of individuals who, in spite of the unlikelihood that they will ever actually meet, and in spite of their different role-related interests, share certain values. Wilson discusses breakfast TV, observing that:

a basic assumption underlying the text, guiding its agendas and focussing its concerns, is that families, whether as viewers or viewed, care about caring... 'Care' is used to mobilise audience consensus around the ethical, often functioning to displace an inevitably divisive political analysis (Wilson, 2005:33).

The mythical 'family of the nation' addressed by TV is bound together by individual relationships of caring and disturbed only by such phenomena as natural catastrophes, institutional corruption and abnormal human wickedness.

It's not that disability is never seen

I want to consider two apparently conflicting comments on the portrayal of disabled people in the media. Roshni recalls her perception while growing up that disabled people were rarely seen in media contexts, while Sarah suggests that disability as a subject is never far from the TV screen:

...I always remember being struck, as a kid, by how few images of disabled people there were ... erm ... on TV, on radio, in newspapers... people that were the same as me, people that I could relate to... (Roshni, 1.2:20ff.)

...there seems to always be disabled people on programmes and things just to raise the issue of disability, not just to show... it sounds silly... but not just to show normality... you know what I mean ... it's always just to show like oh, you're a disabled person bringing up a disabled issue... rather than just being there as they would in normal life... (Sarah, 1.2:26ff.)

One view here suggests that disability is a subject that does not feature largely as part of popular discourse and the other suggests that it is an issue forever being drawn to viewers' attention. While there is divergence of opinion on the frequency of appearances of disabled people, Roshni and Sarah agree that representations rarely involve disabled people they would want to identify with. Disabled characters (usually played by non-disabled actors) appear on television and in film when disability is the subject of a particular story, but rarely incidentally. Disabled people themselves are seen usually only when disability is being addressed specifically, more or less always in order to show what an awful experience it is.

Roshni and Sarah's comments cannot really be compared, as they are doing different things, but it is possible to compare the views that disability is either an infrequent or an all too frequent focus of media attention. My view is that while disability is a fairly constant subject of media obsession this does not negate Roshni's perception that she was unable to recognise in the media many disabled people she could relate to.

Lauri Klobas suggests that:

Television and film's disabled characters have benefitted only marginally from recent social changes. Stories are bound to a confining formula treatment where disability is a personal problem one must overcome. Viewers seldom see disabled characters as multifaceted human beings for whom physical limitations are a fact of nature. Disability is not depicted as being integrated into a busy and full life. For every piece which shifts the focus to the realities and social issues that disabled people face, there are ten fictional TV stories which convey that the *real* problem is emotional. The character has not accepted his/her disability and must overcome the difficulty (Klobas, 1988: xiii).

Klobas identifies ways in which the narrow storylines used to treat disability in the majority of on-screen representations reinforce demeaning stereotypes and horizons which identify disability as a domestic rather than as a social issue. Her *Disability Drama in Television and Film* (1988) is an exhaustive compendium identifying hundreds of appearances by disabled characters (nearly always played by non-disabled actors) in American TV and movies. Many of the titles Klobas lists are familiar enough to British TV viewers of the sixties, seventies and eighties: *Bonanza*, *Little House on the Prairie*, *Happy Days*, *Hawaii Five-O*, *The Rockford Files*, *Superman*, *The Waltons*, *Petrocelli*, *MASH*, *The Incredible Hulk*, *T.J. Hooker*, *Hart to Hart*, *Fame*, *The A-Team*, *The Twilight Zone*, and *The Cosby Show*, for example, all ran episodes and storylines focussing on 'the tragedy of blindness'. Plots

usually involve blind characters being required to face up to their situation and come to terms with it in one way or another.

Klobas gives a summary of *The Hunters*, an episode of *The Little House on the Prairie*, first aired in 1976:

When Pa Ingalls is injured in an accident, daughter Laura must depend on an old blind man to help her find aid... *The Hunters* presented a blind character as one unable to cope with a serious situation, Laura acted as the non-disabled catalyst as she told Shelby he *had* to help. The strong-willed child was in control. Her fear for her father's life drove her. Shelby demonstrated extremely poor judgement when he took on the chore of attempting to find the way out of the mountains since he admitted he hadn't been far from the cabin in years. The action of going out seemingly restored some long-gone confidence as Shelby later indicated he wished to join Ben trapping. *The Hunters* subordinated a blind man to a small child. Shelby's helplessness was self-inflicted due to an inability to accept his limitation. A mountain man who had to live by his wits was devoid of judgement without his sight – or so this piece suggests (Klobas, 1988:44).

I include this extract to illustrate the way in which disability, as a role invalidating the subject position of people with impairments while simultaneously validating the subject position of people identified as unimpaired, is produced within the texts of TV drama.

Klobas' view that disability is rarely far from either the small or big screens is supported by Paul Darke, who expresses surprise that the frequent appearance and use of impaired characters within TV and film has not been noted and defined in terms of what he names *a normality genre*:

Abnormality is used in cultural imagery to define the parameters of normality, not vice versa; it creates the simulacrum through which most apparently 'normal people' live their lives. Thus, there is a coherence, I feel, to disability imagery that has been ignored through a failure to see the role abnormality plays in creating normality; through creating the illusion of normality out of the apparent reality of abnormality (Darke, 1998:183).

Within normality dramas, Darke suggests, physical abnormality represents disorder and chaos so that order and stability can be created as the story moves towards its conclusion:

‘thereby providing both entertainment and a simple resolution to the highly complex social ‘problem’ of abnormality and disability’ (Darke, 1998:184).

Echoing Klobas and Darke, and drawing on Cumberbatch and Negrine’s 1992 study *Images of Disability on Television*, Colin Barnes remarks that:

Disabled people are rarely shown as integral and productive members of the community, as students, as teachers, as part of the workforce or as parents. This feeds the notion that disabled people are inferior human beings with little to offer the community... In TV films and dramas, for example, they represent less than one and a half per cent of all characters portrayed.... Disabled people seldom appear in non-fiction programmes apart from those dealing solely with disability. Moreover, there are no disabled newsreaders, weathermen and women, or presenters of documentaries, and disabled people are hardly ever seen on chatshows in discussions about subjects which do not relate directly to disability (1994:44).

Describing her own early experiences as a ‘real’ disabled person on TV, Lola recounts that:

we got... erm, we used to be on the telly ourselves ... we were occasionally featured in documentaries and ... erm ... all kinds of strange little programmes about the work of Dr Selma Muller and so on, and ... again, I remember that as being ... first of all, always about how you were being made to walk... (1.2:102ff.)

While Lola describes experiences that occurred forty years ago, it is apparent from Sarah’s comment above that this kind of representation of disabled children and adults is still prevalent.

Roshni recalls a time when she was invited to take part in a Radio Four programme:

...one incident that I remember very, very strongly was that a producer who I’d never worked with before from Radio Four phoned me and asked me if I would take part in ... a radio feature they were making ... erm ... and I ... can’t remember the title of this, but it was something really shocking, like ... erm ... *Feel an Elephant* or something ... and this was based on ... I’m sure you know where this is going... this was based on the parable of four blind men who each felt an elephant but felt different parts of the elephant’s anatomy, so when they were asked to describe an elephant’s texture and size, they each described it in a different way... but an elephant is nevertheless an elephant, regardless of whether you find its trunk or some

other indecent part of it ... anyway, they wanted to recreate lots of blind people feeling this elephant ... (1.2:150ff.)

Talking about a Radio Scotland interview she took part in a few years ago, Jennie explained that:

...when people want to talk about disability, they want to talk about people who are living their own lives in spite of their disabilities and all that kind of thing... people who've had a lot to cope with... we talked about other aspects of life to an extent, but there was still this idea of... you know... constantly how bad it must be for me and... well, yes, I know that... I had noticed... but it's not really the focus of anything I do... and I think it... it gives people a disjointed perspective (1.2:87ff.)

Commenting on TV documentaries focussing on the individual lived experience of impairment, Jennie also remarked that:

I do see advertisements for things like that, and am occasionally asked to appear in things... to which the answer is generally a no... not that I'm afraid of the media but I think those kinds of representations are pretty pointless... (1.2:72ff.)

I would take issue with Jennie here regarding the pointlessness of these documentaries, though not in terms of benefiting the disabled people taking part. Just as normality dramas create narratives re-affirming the ideology of normality, so too do such 'factual' investigations. By fixing the objectifying public gaze upon the 'flawed' bodies of disabled individuals, established horizons are strengthened: disability is reaffirmed as an individual problem most appropriately resolved at the domestic level.

I am, of course, aware that the most recent of the quotes I have used from Klobas, Barnes and Darke is twelve years old. In terms of television and film history a decade or two is a long time and it might be objected that arguments made then will not necessarily still be valid. However, it is demonstrably not the case that things have significantly 'got better'. We can identify this by considering Roshni's two following statements. The first relates to her recollections of an awareness-raising film produced in the mid-eighties:

...one thing I do remember, when I was very, very small was that the RNIB made a video with Peter White and a young kid... it was an awareness-raising film about ... you know ... about “This is what blind people are like and look, they can go to mainstream schools and they can do ...” ...but, at that time, to me it was mind-blowing and I remember my family watching this a lot and showing this video to different people and showing it to particularly my grandparents and other people who perhaps had issues with me, as a way of kind of justifying my existence and saying “Look you know, this is ... this is living proof that visually-impaired people can be normal...” (1.2:168ff.)

Roshni’s second statement is about a TV programme she had watched shortly before our second interview:

I think the worst one I’ve seen, to date, was actually on very recently... erm ... and it was made about ... erm ... this college down south...and it was showing the young ... erm ... young visually-impaired... students there ... erm ... and how, you know... “Isn’t it amazing that young blind people can also get drunk and have boyfriends and girlfriends and ... have sex and, you wouldn’t think so but, hey ... they do...” ...erm ... and I thought it was really, really sad to see that ... that was last year ... to see that in 2007 when, you know, we all think that we’ve made these great strides forward and, you know, the radio’s improved, to a certain degree and when you see things like that, I just think... you know... you realize how much is left undone ... erm ... and how little understanding still exists in some spheres ... erm ... (1.2:779ff.)

I find the likelihood interesting that this recent programme would have been regarded by many viewers as a positive depiction of young blind people. Roshni, however, does not consider it this way, for she regards it as just a re-heated version of the eighties video. It is the same narrative and the same story. The location of the blind students within the segregated setting of a residential college would have been taken as unproblematic. Roshni’s point is that if progress has really been made, why is there the need still to point out the normality of blind people? If disabled people were really included in everyday life and within the media then their normality would not have to continually be drawn attention to in TV programmes. Directing TV cameras towards disabled people in order to educate and inform about their normality serves only to confirm their abnormality.

It begins to appear that the problem is not that disabled people are infrequently featured within TV and film, but that when they are shown it is almost only in contexts where impairment is the subject being addressed or the hook for a particular plotline. Rather than being included on their own terms, disabled people are only seen when they are raising disability issues and disabled characters are only seen to remind the majority of viewers of the advantage of normality.

My central argument in this chapter is that even if there is more representation of disabled people in the media now than previously, this does not necessarily mean that it is better representation. Whether there is more representation is questionable anyway: the problem has never been to do with lack of media representation, but with kinds of representation.

Media involvement

There is a consensus among the participants in my research that to have greater involvement of disabled people in media production processes can only be a good thing. To have more disabled people working alongside and actively involved as media producers will, it is suggested, lead inevitably to more accurate and balanced representation of disabled people. This, it is believed, will lead to a more informed public awareness and therefore greater acceptance of disabled people in ordinary everyday life. Talking of her own experience as a BBC trainee, Roshni says:

...you see it as a presence and, you know ... something is better than nothing... to have some form of media presence is better than having nothing at all... and I still think that, to a certain degree ... erm ... you have to put something into the machine to get something back... erm ... you know, we have to work with the media in order to increase the ... erm ... representation that we have got and the accuracy and that's certainly what I was doing ... (1.2:431ff.)

I want to suggest that something else happens. The assertion by disabled people of the right to be different involves an explicit rejection of normality and, in Mitchell and Snyder's terms, 'an act of transgression' (Mitchell and Snyder, 2000:35) which problematises normality. The structural function of TV and the rest of the media is to provide amusement, distraction, and relief to ameliorate the violence performed by capitalism, to normalise rather than provide a critique of capitalism. As Jean Baudrillard notes, transgression never gets on the air without being transformed into something else. There is no better way to reduce the impact of transgression 'than to administer a mortal dose of publicity' (Baudrillard, 1981:173). Increased representation of disabled people within TV is about the creation of

new opportunities to present and recycle stereotypes which reinforce dominant normalising discourses. It is part of a shifting cultural role of TV as a champion of individualisation.

It's care, care, care, care, care...

During our discussion, Charles talked about a news report he had recently watched:

...it was the same the other night, with a report on disabled kids being kept in caged beds... in the Czech Republic... and, you know, there was all the stuff on human rights abuses... blah blah blah... but I think... and they had some people on from the Czech Republic which... quite rightly, considering... and the only sort of social commentary from this country was someone from, I think, the Royal College of Nursing... and it was very much why aren't they being cared for properly... (1.2:76ff.)

Charles' criticism of this report was that, by featuring a nurse as the sole UK commentator upon this story, its impact as a report on human rights abuses was undermined. The grounds for considering the situation of these Czech disabled children in political terms as a rights issue were undermined by requiring the story to be understood as a care issue. The nurse's intervention ensures that these children will be recognised only as children with 'special needs' who need decent care within segregated institutions. Charles asks:

Why didn't they have a disability rights campaigner on... or someone like Rachel Hurst, you know... that's her area... and she would have spoken far stronger... (1.2:82ff.)

It is more likely that it simply never occurred to the producers of the news programme to invite a disability rights campaigner to speak on this matter rather than that a conscious decision was made not to do so. There are several consequences of this for the way the story was framed. The possibility of its consideration as an independent living or as a segregation issue was precluded. If anything, what is inferred here is that, while disabled children experience neglect in 'far away' countries like the Czech Republic, such things do not happen here where they receive proper care. What is not challenged here is the assumption that care is the only appropriate social response to disability (Oliver, 1996).

Charles continued by making a further observation on the ubiquity of the word *care* within television discussions on disability:

...another report on Sunday I watched on *The Politics Show*... and it was a report on Individual Budgets... it really caught my eye because you very rarely see anything

on Direct Payments or Individual Budgets on television and in the media... but, again, they filmed someone who uses an Individual Budget... and, you know, she was very nice and she was saying *it makes my life much better... I bought a scooter with the money so I can get out and about blah blah blah...* but then the debate and discussion was between... what's he called... the minister for care... I can't remember... and they had the shadow minister... for care... or whatever... but, again, there wasn't a disabled person there in the discussion... and it was 'care' this and 'care' that... care care care care care... (1.2:93ff.)

Charles' frustration at the media's inability to discuss disability in terms other than as a care issue expresses a view widely held within the disabled people's movement:

The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives (Wood, 1989:unpaged)

So long as the subject is publicly couched in terms of care the horizons framing popular perceptions of disability are left undisturbed. As Pierre Bourdieu remarks, TV news 'suits everybody because it confirms what they already know and, above all, leaves their mental structures intact' (Bourdieu, 1998:45).

Charity begins on TV

Helen noted the fact that when comment on news stories about disabled people is looked for it is usually charity professionals who are approached:

...if there's a comment to be made on any of these type of things in the paper... people will go to a disability charity to get a comment on it and ... I don't know whether it's the people in the media that don't seem to realise this ... erm ...but obviously somebody working for a charity doesn't necessarily have that disability but ... once they're in the media they are representative of that disability (1.2:542ff.)

Disabled people's organisations are rarely invited to comment on disability issues in the media. It is presumed that the large charities will speak on their behalf. While there are issues here relating to the opportunism of charities in pursuit of publicity, I would also argue that the media benefits from its promotion of these organisations. Each is necessary to the other as each feeds off the other.

Within what Guy Debord has termed *the Society of the Spectacle* (Debord, 1990), the media has an active role in creating what passes for reality. For example, the media and the big charities work hand-in-hand to ensure maximum public participation in money-generating

pseudo-events such as *Children in Need*. A *pseudo-event* has a number of closely-related and self-validating characteristics:

1. It is not spontaneous: it has been planned or spun in advance
2. It is produced, from the beginning, in order to be reported or reproduced
3. Its relation to any underlying concept of reality is unclear
4. It is an essentially tautological phenomenon

(Taylor and Harris, 2008:117)

Children in Need and related pseudo-events actively undermine the identification of disability as an issue of discrimination and oppression by ensuring that the whole business of supporting disabled people is seen as *fun*. Focus is interspersed between the ‘madcap antics’ of celebrities who have ‘selflessly’ given up their time to get involved and heart-rending images of tragic disabled children who will benefit from monies raised. Paul Taylor and Jan Harris contend that reportage of *human interest* stories within pseudo-events relates:

more to the motivations and the psychological contexts surrounding the actors involved in various pseudo-events, rather than any actual substantive significance to the events themselves (Taylor and Harris, 2008:117).

Focus is directed at emotional aspects of pseudo-events without any attempt to address the issues in a political context. To begin this would spoil the enjoyment of it all and, as Neil Postman has pointed out:

Entertainment is the supra-ideology of television. No matter what is depicted or from what point of view, the overarching assumption is that it is there for our amusement and pleasure (Postman, 2006:87).

Saturation media coverage of pseudo-events, reminding us of their own importance, ensures they are regarded as important. The real significance of events like *Children in Need* is that they confirm for individuals the mythical national family made up of other individuals like themselves who care. Taylor and Harris comment that:

The self-referential media community that decides the newsworthiness of items is reinforced by a cultural environment in which knowledge of pseudo-events

increasingly becomes more important than more traditional forms of knowledge (Taylor and Harris, 2008:119).

Giving to charities for disabled children through pseudo-events such as *Children in Need* provides endless opportunities for individuals to validate themselves by demonstrating that, along with millions of other big-hearted individuals they will never meet, they care.

Commenting on *Children in Need*, Ben told me that:

It sickens me to be honest... but it's very difficult to say anything against it in the wider community... within the disability community it's despised and hated, but when you're in the wider community... if you happen to be in a pub and someone comes in raising money for it... with a large bucket... you just don't feel as if you can say anything about it for fear of the consequences... so, yeah, socially reinforcing in that sense... it's self-policed by majority consensus... (1.2:227)

The voices of disabled people who would offer a different perspective on the role of charity go unheard amidst the clamour of generosity and pity as the wider community meets its own needs to have its horizons reaffirmed. As Ben also observes, it is not as simple as saying that disabled people object to pseudo-events like this, because there are plenty of disabled people who are happy to endorse them:

...a certain college I used to go to, they'd raise money for *Children In Need* and all that... it's part of your moral education... reinforced in the schools... and in the literature... it's not considered to be oppressive to do that... because it's never considered from the other perspective... cos when you're in that perspective you're not allowed to say it... it's just a hidden, suppressed perspective... (1.2:310ff.)

Ben draws attention to the recruitment of disabled children and young people as subjects within this disability discourse. There is no other available narrative because the alternative narrative is never listened to or has been watered down until it has become unthreatening and is couched in terms of 'people with disabilities'. Those disabled people who regard disability as oppression are dismissed either as irrelevant extremists or as heartless and uncaring. Ben's comment is supported by Roshni, who recalls of her schooldays:

...we had a lot of visits, as many people did at that time, from *Children in Need* and all these sort of charity– inspired telethons and game shows and all of that, and they all came and filmed us ... erm ... and... and I remember that striking a lot of chords

with me, because the very first time that that happened, I remember that all of our family and different relatives and some close friends packed into the house to see these disabled kids on TV of which I was one... but I remember being struck by how much of an impact this was having, in terms of striking at peoples' emotions and everybody saying how amazing this was and these *poor* disabled children ... and it was so wonderful to see them on TV and that they were getting this money... (1.2:28ff)

Jennie argues that it is never as simple as saying that people just believe and do what they are told by the media (1.2:690ff.). She is concerned, however, in relation to disability about the impact when only a certain type of representation is portrayed:

...the impact of seeing it again and again... of seeing it in several different forms of media... I think that's more problematic... it would be nice to think that people could make all their decisions independently of the media, but really people make their decisions based on how different media interact with each other... someone might think well, that was only in a film... but when they see something on the news that shores it up a bit, and they see things in magazines... it just... things seem to be everywhere then and you get a sense of normalisation of a particular attitude... and it's normalisation which is really the issue... (1.2:698ff.)

The sense that it is impossible to escape the charity model of disability is expressed by Mary:

I mean, just in the Co-op, which should know better but, say no more ... erm ... we have people dressed up for Red Nose Day, you know... where was I... I was in TK Maxx on ... last week, right ... and they're running two things simultaneously now... one is for ... erm ... initiatives in the majority world, right ... I'm not sure which it is ... it's clean water, I think ... but, the other thing is ... erm ... oh, it was ... erm ... I think it was MacMillan or Sue Ryder, right ... and I was asked ...would I want to give a pound from my change to whichever one it was that they were collecting for that day...it's all-pervasive ... (1.2:597ff.)

Celebrities, Charities and Children

I've just come out of a meeting with a voluntary organisation I'm on the board for, and we need figureheads... it's one way of getting instant media attention and therefore getting into other people's consciousness... (1.2:167ff.)

Anne's statement here reflects the extent to which the association of celebrity, charity and media is unquestioned within contemporary culture. Representation by celebrities is perceived by many charities as ensuring access to media coverage and income-generating publicity.

Taylor and Harris cite Theodor Adorno's argument that the culture industry relies on an unhealthy denial of the marginal nature of the supposed differences between what are essentially the same commodities. The illusion of difference, they suggest, is created by the advertising industry's manufacture of superficial distinctions and purported attributes, this holding as true for celebrities as brands:

Successfully advertised goods mean that inanimate objects become celebrity products. For a human celebrity well-knownness creates its own justification (Taylor and Harris, 2008:134).

Celebrity is a brand which needs constant promotion if it is to retain its glamorous appeal and is haunted by the prospect of fading into obscurity. Just as charities rely on celebrities for media exposure, so celebrities rely on being associated with charities to remain in the public eye. Describing the frequency with which her special school in the East End of Glasgow was visited by stars of sport and TV, Roshni recalls that:

Andy Cameron, who's now a little-known celebrity but, at that time was very popular ... erm ... he lived just down the road from us ... erm ... and he was always ... visiting us with one thing or another ... (1.2:1540ff.)

Helen comments on the tendency of celebrities to associate themselves with 'cute' impairments that will, when televised, pull the heart strings.

...it tends to only be ... I don't know ... *nice* conditions ... but, you know, kids with leukaemia are something cute... erm ... you don't get charities for people with horrendous skin complaints that make them look really horrible ... that's not gonna get on the front page... (1.2:1571)

Helen's observation is reiterated by Kevin:

...you wouldn't see someone scratching on television, for instance... specially if they had an itchy groin or something... (1.2:311)

To be shown with people whose impairments might make viewers recoil in disgust would be to spoil the image. Anne Finger writes of media and celebrity fondness for awareness-raising campaigns for conditions like leukaemia:

...those pallid young children wasting slowly into death. No ugly protruding tumours. No convulsions, no spasms, no missing limbs (Finger, 1994:115).

Mary discusses the use of children in charity advertising by comparing campaign posters produced in the 1960s and in 2005 by The Spastics Society and the same organisation re-branded, Scope. The 1960s poster bore the prominent alarming statement *It could have been your child* and depicted:

a lovely little girl, of course ... pretty, pretty ... hair in bunches and she's probably about ... don't know ... four, five, right ... and she's on callipers, right ... and behind her, in the background are some other children with mobility aids ... (1.2:523ff.)

Describing the 2005 poster, Mary says:

it's got nine little kids and they're all ... you know, three, five, right ... all dressed up in different things like there's a paramedic, erm ... a doctor ... erm... what else is there... painter ... you know, all these kinds of things... they look like the Village People, yes... without the er ... the er ... Native American, 'cos obviously there isn't a job being a Native American ... right, erm ... but, but they're an ethnic mix and ... it's, it's apparent that some of them have impairments, right... erm ... obviously and, you know ... it says... the strapline for this is *Want to Work? We Do...* (1.2:529ff.)

Both posters rely on images of cute disabled children to make money. Mary describes her annoyance as being about the fact that this kind of imagery involves:

...the infantilising of disabled people ... right ... why have children... well, obviously you... you're using children because it's emotive and also ... they're cuter than disabled adults... (1.2:615ff.)

It seems obvious to suggest a cynical link between the use of images of children and charity income generation, but I suggest something deeper is also going on. Julie Shaw Cole and Mary Johnson argue that:

Society really does view all disabled people as kind of perpetual children – still, despite laws, despite all the talk, despite all the *awareness*... Vulnerability, lack of capability, immature abilities – these are all traits that we, as a society, want to deny in ourselves – that we seek to project onto others. Who better to project them onto than disabled people? And that's what society's been doing. It's a lot easier to project one's vulnerability onto someone else – a disabled person – than to have to face it personally (Cole and Johnson, 1994:134).

There exists a gulf in terms of celebrities' roles and disabled people's roles in relation to the charity business. While this is typically represented in terms of benefactors and beneficiaries, I suggest we can also regard what is going on in terms of symbolic enactments which sustain the values of individualistic capitalism. Richard Dyer observes that:

stars articulate what it means to be a human being in contemporary society, that is, they express the notion that we hold of the person, of 'the individual' (Dyer, 2003:8).

Through processes of marketing and management the celebrity is constructed to embody the values of freedom, independence and individualism. As charity figurehead, the magnetism of celebrity (regarded in terms of unique talent) draws the public gaze to the plight of the nameless disabled. The contrast could not be greater. Dyer suggests that fascination with celebrity is related to the need to make sense of experience in terms of contemporary social organisation:

We're fascinated by stars because they enact ways of making sense of the experience of being a person in a particular kind of social production (capitalism), with its particular organisation of social life into public and private spheres. We love them because they represent how we think that experience is or how it would be lovely to feel that it is. Stars present typical ways of behaving, feeling and thinking in contemporary society, ways that have been socially, culturally, historically constructed (Dyer, 2003:17).

The sight and association of celebrity alongside its symbolic opposite, dependent disabled nonentity, serves to naturalise horizons within existing structural relations. Taylor and Harris remark that:

while the essential elements of the commodity system remain undisturbed, celebrity faces effectively distract us from the much less glamorous and more mundane

structural economic causes that continue to dominate social relations... As embodiments of the enigmatic and irrational aspects of commodity culture, even their various well-intentioned charity campaigns ultimately serve to reinforce the system as they appear to challenge it (Taylor and Harris, 2008:134).

Another view, quickly dismissed

Offering a different perspective on the roles of TV and celebrity in the construction of everyday life, Laurie Ouellette and James Hay propose that TV - in particular the phenomena of so-called Reality TV – plays a major role in the empowerment of individuals. They contend that whereas in the past viewers were regarded as ‘a gullible mass that needed guidance in the liberal arts to participate in the rituals of democracy’ (Ouellette and Hay, 2008:3) TV now treats its audiences differently, in that it ‘circulates informal *guidelines for living* that we are all (at times) called upon to learn from and follow’ (Ouellette and Hay, 2008:2). Rejecting structural analyses, Ouellette and Hay argue that:

these are not abstract ideologies imposed from above, but highly dispersed and practical techniques for reflecting on, managing, and improving the multiple dimensions of our personal lives with the resources available to us (Ouellette and Hay, 2008:2).

Ouellette and Hay suggest that Reality TV programmes provide resources for viewers’ private self-empowerment. They are to be consumed as part of:

a dispersed network of supporting technologies geared to self-help and self-actualisation (Ouellette and Hay, 2008:3).

Similar arguments have been made with regard to celebrity gossip magazines such as *OK*, *Hello!* and *Heat* (Turner, 2006:74). It is not the content of such commercial products that is regarded as important so much as the way they are used by knowing audiences, who use celebrity material ‘for play, for experimentation, as fodder for their own cultural activities’ (Turner, 2006:111).

Reality TV programmes such as *The Osbournes*, which recorded the domestic life of heavy metal singer Ozzy Osbourne and his family, invite viewers to observe the mundane familiar patterns of family life shared between themselves and the stars. The impression is conveyed that, after all, celebrities are just individuals like them and that bourgeois patterns of living and relating to each other are right and natural.

Unsurprisingly, I reject Ouellette and Hay's analysis. While popular cultural texts such as Reality TV programmes and celebrity magazines may be used creatively in everyday life, I would contend that, rather than being empowering, this involves self-adjustment, learning to cope and making the best of things within capitalist structures. It involves an acceptance of alienating social relations.

Lola offers further insight into this matter:

...we live in that kind of age anyway where, you think about it, there's an obsession with celebrity, isn't there... and there's an obsession with peering and prying into other people's lives ... and maybe that's a strange facet of that obsession that then reinforces ... erm ... a lot of these issues for disabled people anyway ... erm ... maybe it's a sign of the ... the flipside, almost ... because when you think of how obsessed we are or how obsessed society is with ... erm ... you know, celebrities being physically perfect and waiting to see ... erm ... you know, if something goes wrong with that or they develop a flaw or a spot on their arse or whatever it may be ... erm ... and I can't help feeling that disabled people are somehow ... that we're like the polarization of that ... (2:681ff.)

While the social roles given to celebrities and disabled people are perceived as vastly different, Lola suggests that both groups perform similar functions in terms of focussing the public gaze on individuals.

Documentaries

Charles talked about what he described as:

a new breed of documentaries that are very popular... whereby they'll focus on one disabled person... or maybe sometimes two, but normally just one... for an hour... (1.2:590ff.)

Participants' perspectives appear to diverge on the purpose and value of contemporary disability documentaries, ranging from fairly positive to disgusted. One view regards these programmes as relatively factual, objective and socially useful. As Anne says:

I think some of the documentaries they make are actually... depending on the documentary maker... fairly well-observed... and there's a series on at the moment called *Extraordinary People*... which seems to be focussing on people with very, very rare conditions... such as conjoined twins, et cetera... which has always been a

source of... what's the word I'm looking for... interest... to other people... but some of them are very well-observed... and they will raise issues about things like the availability of drugs... the choices parents have to make... the lack of information the parents have... whether or not the parents' income is having an impact... they'll talk about the impact on siblings, et cetera... all these kind of issues... some of them are very well-made... there's no doubt about that...(1.2:123ff.)

Anne regards such programmes as having value in raising awareness of the social issues experienced by disabled people and their families. She refers to a specific programme in the series *Extraordinary People*:

...they had an interesting one about a girl who had a parasite conjoined twin who, obviously, wasn't alive as an individual... she had the equivalent of eight limbs... and she was born in an Indian village where the local goddess has eight limbs... and as far as they were concerned she was the local goddess... and her parents were rural subsistence farmers... who had bought into this idea that this child was a reincarnation of the goddess... and potentially this was their way out of poverty... I never saw the thing right through, so I don't know what decision the parents made... but I thought that was well-presented... that it showed the background to the parents... (1.2:321ff.)

Ambivalence about such documentaries is voiced by Ali:

...you see documentaries... like the *Amazing People* documentaries... people with massive... problems with their legs and stuff... it's portrayed as interesting, but you wouldn't want to... it's more... it's just more out of fascination than... like this freak show idea... like they're just freaks... you know... that's why I watch it, just cos... you know... but I wouldn't want to be them... and these documentaries seem to portray disability just as... it's something like *Big Brother* or something... it's just something to watch... for example, there was this one documentary where this guy had a really, really badly deformed face... and he could hardly see, he was blinded, and people just looked at him, you know... but in a way I can't knock entirely... I mean, also these documentaries kind of show disability in a way that would... in a good way as well... because they do help... you know, not to look at people and to point at them, you know... people who might have deformities on their face... so I think now that maybe it is getting better in that sense... (1.2:58ff.)

Initially Ali confesses to watching programmes like this for their entertainment value. His statement *it's portrayed as interesting* suggests that he is unconvinced by the suggestion that such documentaries are primarily intended to be educational. His description *this guy had a really, really badly deformed face* emphasises the ghoulish attraction such programmes hold for viewers.

He then, however, questions himself, asking whether, after all, there may not be some useful social purpose served in such portrayals of impairment. He suggests that perhaps watching people with disfigurements like this on the TV screen will have some sort of normalising impact: as if greater knowledge about the medical aspects of certain conditions will lead to an easier public acceptance. In his concluding remark, *I think now that maybe it is getting better in that sense*, he completes his reversal from his original position. From having started off describing these documentaries as portraying freaks to be gawped at, he has moved to suggesting that such representations are part of a general progressive shift in attitudes.

Similar uncertainty about how to regard this sort of programme is expressed by Ash:

...there was a programme on very fat people and how they're so different from everybody else... and here, we've got Siamese twins and we'll film them being separated... and everybody looks in and watches it... I know it's maybe helping in a way to show these things, but... I don't know if it's like the circus, you know... you pay to see the bearded lady and you go in and these people are different... they deal with it sensitively... I don't know... maybe that is helping in a way... (1.2:431ff.)

Ash is undecided about whether documentaries are helpful, having a role in dispersing socially useful knowledge, or whether they are more like circuses, drawing attention to human abnormality for purposes of titillation and profit. His uncertainty seems to be compounded by his perception that these subjects are dealt with sensitively: as if a difference is made by the absence of gaudy paintwork, rolling drums and a man with a waxed moustache in a top hat inviting us to roll up and take our seats. (A faceless link person now performs this function.)

What I find interesting in Ash's statement is the impression that, while he seems initially sceptical about programmes like *Extraordinary Lives*, he also appears to doubt his grounds for scepticism. *Maybe that is helping in a way...* he says, wondering whether perhaps he is wrong to dismiss something which is obviously factual.

Charles has no doubt about the nature of this type of documentary:

I called them the 21st Century Freak Show... that's exactly what they are... you don't have to pay to go and stare at someone in a cage... you've got them in your living room... every night at 9 o'clock... either Channel 4 or Channel 5... or if you've got Sky you've got whole channels... and it's not just a British thing... there's plenty of these things coming over from America as well... (1.2:609ff.)

Charles believes that the primary function of such programmes is sensational. Human bodies regarded as abnormal are displayed in forensic detail in order to emphasise the advantages of normality. Charles talks about the cynicism involved in the production of documentaries like this:

...very often it's someone who's not particularly empowered... and they can get away with saying anything about them... and portray them in any way... so I think it's really exploitative... and obviously they're going for the sort of tear jerking reaction, aren't they... (1.2:590ff.)

He illustrates his point:

... the classic one was that documentary last year... *Age 12 and Bringing Up The Family* or *Looking After the Family*... where... I mean, it was so biased... they filmed these two families where there were kids that were disabled young carers... and... yeah, one family seemed relatively coping... the other family was a blind couple... and I think one of them had learning difficulties as well... and they had eight kids...and there's one bit that sticks out, where the baby was, like, crawling around on the floor... and the interviewer asked the dad, you know, "Isn't that dangerous... what if you step on him..." and he said "No, that's OK... I dress him in contrasting colours to the carpet... so he stands out..." ...and you can kind of see what he was getting at... but the way he said it sounded so callous... (laughs)... and again, what was interesting was they filmed these two families... one was relatively... you know, getting on with it... the other family were just... I mean... it was appalling... they weren't good parents... they were really awful parents... but that made good television... so they devoted, like, three-quarters of the programme to them... and one quarter to the other family... cos it was obvious they'd set out to film two families, going *Oh, my God, this is brilliant*... (1.2:52ff.)

Charles' suggestion is that making good television is the primary intention of documentary makers. In the details of the documentary described above – the narrowness of the focus (two families), the family-oriented focus, and the far greater focus upon the family perceived

as 'awful' - we can see again the way in which the media simultaneously promotes and sustains horizons of domesticity and assumptions around normality and abnormality.

Culture as management

We gain further understanding of the role of current disability documentaries by considering Gareth Palmer's argument that, as the chief focus of leisure for millions of people, TV is:

part of the work of culture-as-management, where culture is a set of practices aimed at producing – in line with governmental objectives – self-regulating, self-governing individuals (Palmer, 2003:18).

Palmer argues that early TV documentaries gathered and presented the voices of diverse individuals in order 'to make reasoned cases for change in the social sphere that they were simultaneously trying to create' (Palmer, 2003:7). He asserts that pre-1979 the documentary form was used to encourage and develop critical debate around issues of citizenship within the welfare state, to problematise institutions, issues and situations. An educational purpose was assumed as the function of documentary within a context in which TV was understood as having a public service role:

Documentary workers were licensed to criticise the operations of the State while still deriving their income from publicly funded bodies such as the BBC or in the relative security (in today's terms) of independent television (Palmer, 2003:8).

The shake-up of consensus established by the arrival of the Thatcher government of 1979 led to an overt celebration of the individual over the social. As with many other cultural forms, this had an impact on TV documentary, which increasingly addressed viewers as consumers rather than as citizens. The focus of documentary shifted from analysis of social issues to individual behaviours. Palmer states that while new populists argue that docu-soaps and Reality TV formats are changing documentary in positive ways, what he sees is a growing mechanism of panopticism:

Such mechanisms ensure the docility of the body as more and more aspects of life are made more open to examination. Such examinations in turn form new types of knowledge with which the problem of population can be managed (Palmer, 2003:6).

Charles echoes Palmer:

...it seems to me that documentary making has moved more towards an individualistic focus and away from an issue focus... and obviously, from the point of view of disability rights it's a lot harder to talk about these issues on an individualistic basis... but if you're focussing on an issue then you'll interview various people and get a number of different viewpoints... but you're getting that less and less... you're not getting documentaries where they juxtapose different perspectives, are you... you're just getting one person saying this is my life... this is what I do... (1.2:637ff.)

While it is possible to regard any increasing media representation of disabled people as signifying progress and an increasingly inclusive society, my own argument is that this can be rather seen as part of a shifting focus of governance, one which aims to hold individuals more accountable by making them increasingly responsible for their own behaviour. Programmes directing the public gaze at people with impairments are part of a myriad of new formats depicting 'the irregularities and incivilities of everyday life to enable us to pass judgement on fellow citizens' (Palmer, 2003:14). They need to be considered alongside programmes about dodgy builders, recalcitrant drivers, unpleasant airline travellers; or about the interpersonal conflicts between residents ensconced together in a house or celebrities stuck in a jungle for several weeks. Seeing squabbling disabled people on Reality TV programmes such as *Beyond Boundaries* and *Britain's Missing Model* seems less to do with valuing diversity than with a combination of sentimentality with what Richard Hoggart calls 'Ooh-ah' appeal: 'a mixture of fear, cruelty and collective self-righteousness' (Hoggart, 2005:55).

Reality TV

Quicksands, predatory big game, unforgiving desert, oppressive heat, swamps and the extreme white waters of the African wilderness – as well as the usual poisonous snakes and insects - will be faced by an intrepid team of disabled people in the second series of *Beyond Boundaries*... (BBC, 2005: unpagged).

Speaking as someone selected for interviews to be a member of the team of disabled people for the second series of the BBC2 reality documentary *Beyond Boundaries*, Sarah says:

I think it's really good 'cos its allowing people insight into some of the issues... but then, other people say I find it really patronising... so it goes back to the bit about, you're never gonna please everyone... cos it depends on how you ... like ... how

you've been brought up and how you view your disability on how you're gonna view the representation.... (1.2.378ff.)

Sarah highlights two conflicting opinions about *Beyond Boundaries*. The first is that it is 'really good'. Observation of the interactions between team members, which is the main focus of the programme, is perceived by Sarah to allow people some insight into the issues involved in being disabled. The second is that, as a programme, it is 'really patronising'. Sarah's perception is that individual interpretation of this show will depend largely upon socialisation and how impairment is understood.

Sarah's description of being part of the selection process for this second series is revealing:

I remember saying it... what *is* the aim of the programme... obviously I know what the aim of the programme is, it's to get people to watch and sometimes having people arguing and having arguments is what people wanna watch... but, when it's an expedition should it not... should the team members not be like all ... everybody wants to get to the end and I said that I found it quite bad that people were allowed to bully people like that... and they were like oh well, it's TV, the cameras are there, we can't control what people do when the cameras are there... (1.2:395ff)

While recognising that the aim of the show is to show people arguing (in which regard *Beyond Boundaries* is no different from any other Reality TV show), Sarah recalls at the interviews expressing disquiet at the fact that in the first series bullying of some team members by others had been allowed and shown. To Sarah's mind this was not the spirit of what journeying across the Andes should have been about. The production team's reply was to shrug: "Nothing to do with us."

...and it was quite interesting being in the process of how people were selected because it was really varied disabilities and different outlooks on stuff and I'm ... well, just you had some people that were like ... who were disabled, but they were like... I'm *not* disabled... I don't *allow* myself to be disabled... and then you had other people who openly... like, they hadn't dealt with things.... (1.430ff.)

In the pursuit of good television, careful planning appears to have gone into the selection of participants who would conflict with each other. I would suggest that the two different positions that Sarah identifies here (that which says "I'm *not* disabled... I don't *allow* myself to be disabled"... and that of disabled people who 'hadn't dealt with things') represent both sides of what I have identified as *the disabled role*. Neither regards impairment as ordinary

experience. The first regards impairment as tragedy to be triumphed over while the second regards impairment as tragedy to be suffered.

The BBC press release quoted above continues by adding that:

Roly Keating (*Head of BBC2*) comments: "Beyond Boundaries is emotional, thrilling and compelling TV... one of those rare programmes that genuinely challenges the way we look at the world" (BBC, 2005: *unpaged*).

I find it difficult to regard Keating's comment as other than cynical. The central purpose of *Beyond Boundaries* is to depict people arguing. The fact that the team happen to be disabled is a variation on a format which gives it selling appeal, but to suggest it 'genuinely challenges the way we look at the world' is pushing things beyond credulity.

Noting that 'basically the BBC's budget for disability programmes for the last two years has been spent entirely on that' (1.2:482), Charles observes that:

...every stereotype is there... this whole thing of... I love the first clip...with the visually-impaired guy... "There's either one of two ways... you can be either bitter and complain... or you can get on with it..." (1.2:483)

Charles refers here to one of the video clips he has shown me, in which one of the *Beyond Boundaries* participants has outlined to viewers his view of the two options open to disabled people - either become bitter and twisted or triumph over your tragedy:

...it's the chip on your shoulder stereotype, isn't it... you know, if only you changed your attitudes then the barriers would go away... (1.2:497ff.)

What Charles identifies as oppressive is that, while two options are held out as possibilities here, both identify resolution in individual terms. Taylor and Harris argue that:

Reality TV, despite appearing as a naturalistic guise that does not have a meta-narrative, performs its important ideological role by taming the potentially transgressive (Taylor and Harris, 2008:163).

Through careful selection of its participants, as described in Sarah's comments, the possibility has been eliminated that a transgressive view might be voiced. Viewers may

debate the choices that are displayed, but care has gone into ensuring the radical option will not be heard. Taylor and Harris also note that:

...essentially empty, tautological and vacuous media content can still be fascinating in an absorbing rather than revealing sense. It produces much interpretive activity (the focus of cultural populism), but from a critical perspective this activity reflects, rather than challenges, cognition's enervation (Taylor and Harris, 2008:155).

To reiterate a point, while *Beyond Boundaries* may generate discussion, this discussion functions to buttress existing horizons rather than to 'change the way we view the world'.

You're being told that you've got to fight against... fight and conquer your disability... it is completely unrealistic, isn't it... the issues for most disabled people are around getting a job... getting an education... getting around from place to place... not traversing through Africa... or going through a swamp, up mountains... these are not the issues... yet these are the issues that this programme presents... (1.2:518ff.)

Charles' draws attention to the way that the location of *Beyond Boundaries* (Series 1: Nicaragua; Series 2: The African Challenge; Series 3: Across the Andes [BBC, 2009: unpagged]) decontextualises the experience of disability. To have filmed the same individuals attempting to work as an intrepid team in order to traverse Edinburgh or Newcastle might have produced more interesting questions.

Discussing the way in which *Beyond Boundaries* objectifies the disabled people taking part, Charles remarks that:

...the narration is like *Wildlife on One*... it's like *see the disabled people out of their natural habitat*...

While it is presented as an imaginative, progressive media representation of disabled people, I argue that *Beyond Boundaries* is simply an updated version of the 'strange little programmes' (1.2:103) that Lola used to appear in. Both encourage the view that disability is something that can be overcome with a positive individual attitude. Both preclude the suggestion that resolution might be looked for in the social sphere.

Charles illustrates the way in which media feed off each other to sustain horizons:

Ade was another *Beyond Boundaries* contestant... he's probably one of the most recognisable disabled people in the country... and there was a *Guardian* interview with him that I read... and the interviewer asked him is your house... is your home adapted to be accessible... at which point he got angry with the interviewer... and he was saying "I don't have nothing like that... I just get on with it..." ...and the interview said that's great... what a message to put out... similarly *The One Show*... they had this sort of feature on people going back to the houses they grew up in... and they had Tanni Grey-Thompson... going back to her house... and she said my dad was the architect but they didn't adapt the house in any way because they thought it was better that I pull myself up the stairs... you know... and adapt to my surroundings... cos that would serve me well in later life...

I suggest that TV programmes like *Beyond Boundaries* create disabled celebrities whose role is to perform the same function as any celebrities: of naturalising perceptions which reduce social issues to individual challenges. Because they are disabled 'achievers' Ade and Tanni are held up as exemplars, not only to other disabled people but to non-disabled people too. The never-ending round of self-congratulation in which the media indulge distracts from structural causes of inequality: young disabled people are encouraged by Ade and Tanni to overcome their limitations; older disabled people who have never been Ades or Tannis are reminded of their own inadequacy.

Simultaneously, as Ben points out, a disciplinary discourse is being imposed on non-disabled people:

disability is used... as a warm, human interest story... as a sort of morality fable... but still in order to say if a disabled person can do this...if someone can do it in spite of all this difficulty, why can't you... you don't have all these barriers and 'handicaps'... so you should think yourself so lucky to be who you are and able to do what you can... so you ought to do something moral with that... instead of just having a good time... (1.2:456ff.)

Stereotypes

We may not realise it, but very often we learn about other people through what we see in the mass media. This is especially true when the other people we're talking about are different from ourselves and we have little face-to-face contact with members of their group... When we fear or reject the influence of mass media, we make ourselves vulnerable to being directly used or manipulated. In the case of

media stereotypes – of race, age, sexual orientation and other social categories – we open ourselves to seeing through the eyes of the media instead of through our own eyes (Dill, 2009:89).

While I dispute Dill's supposition that it is ever possible to see through 'our own eyes', so culturally structured is our life experience, I agree with her main point – that it is easy to let media representations shape our understanding and knowledge of people beyond our direct experience. Developing this discussion, Dill distinguishes between what she describes as positive media communication of social information and information which reflects a pre-packaged, mass produced vision, driven by media producers' desire for profit above other motives:

Producers may have hidden agendas. They may simply tell a story for the shock value of it in the hope of getting ratings. The producers themselves may help create a story so they can report it and gain an audience for their advertisers. Or perhaps those who produce the story have a personal interest in telling a story in a personal way (Dill, 2009:90).

It is easy, suggests Dill, to digest 'a vision of how life is without questioning it' (Dill, 2009:90). In her discussion on the way media stereotypes work to reinforce existing relations of inequality she focuses on race and gender. The example she gives of 'positive media communication of social information' focuses on impairment. She describes listening to a National Public Radio story told by NPR's science correspondent. The story was entitled *Susan's First Snowfall* and described how:

Susan – a visually impaired woman who had never seen the world in three dimensions – underwent a treatment that miraculously gave her binocular vision for the first time in her life. Through the interview, Susan relates that snowstorms had always looked more like distant white sheets than like individual flakes dancing around her. I am mesmerised listening to her describe being overwhelmed with the joy of seeing the big flakes of a snow shower falling lazily around her for the first time (Dill, 2009:89).

Dill says that this is positive media communication of social information because:

I have never experienced what Susan did; I didn't know about her condition or its treatment or what it would be like to go from 2D to 3D vision. But after listening to the story, I feel like I understand something about the essence of that experience

from afar. I've picked up information about a group of people – those with visual impairments – and I've learned something about their struggles and triumphs through NPR's telling of this woman's story. I've also learned more about perception and medical science (Dill, 2009:89).

I suggest that Dill has picked up information about *one* woman with a visual impairment rather than about 'those with visual impairments'. Having learned about Susan's condition and its treatment in a story narrated by a science correspondent, Dill's perception that the proper place for discussion of disability is within terms of a medical discourse has been confirmed. In having heard the results of Susan's treatment described as 'miraculous' her view that what went before was second-rate is reinforced. I would question whether Dill has learned a great deal about the 'struggles and triumphs' of people with visual impairments so much as she has unquestioningly accepted as enlightening a repetition of the personal tragedy narrative. The subject position of people with impairments is invalidated (things were so much worse for Susan before her treatment), while that of people perceived as unimpaired is validated (being able to see is so much better).

I find this interesting because of Dill's apparent inability to recognise the stereotypes apparent in Susan's story even as she addresses the subject of stereotype. Where we look for stereotypes, as Dill does with regard to race and gender, they are obvious. Where we do not, they are obscure. During my interview with Rose, she admitted that:

I have to say, also, that when you said in your email to start looking I thought that nothing would turn up... but quite honestly, after two weeks... it only took two weeks... for everything we're talking about now... so that shows you how saturated it is... (1.2:550ff.)

During a short period of what she considered to be typical viewing and listening for her, Rose watched and listened to a variety of TV and radio programmes, including dramas, quizzes and comedies, and had noted disabled people portrayed and discussed as rejecting identification as disabled (1.2:99ff.) as objects of comedy (1.2:261ff.; 1.2:378ff.); as needy and dependent (1.2:275ff.); as mad (1.2:292ff.); as objects of exploitation (1.2:380ff.); as poor victims (1.2:421); as childlike (1.2:475ff.); as slow and stupid (1.2:528ff.); as murderous (1.2:559ff.); as frauds (1.2:563ff.); as helpless burdens (1.2:580ff.); as unattractive and asexual (1.2:610ff.); as being of less value (1.2:617ff.); and as bitter and spiteful (1.2:640ff.)

Rose comments that:

I didn't start noticing them until I started looking for examples, so I wouldn't even have noticed them before I knew this interview was going to take place... so I can only say that... erm... there's a sort of insidious creeping into the unconscious mind of negative characteristics of disabled people, going into... our common culture, our wider culture... (1.2:297ff)

While popular cultural stereotypes of disabled people abound, it is not until we focus our attention that they become apparent. It is worth comparing Rose's list with a list produced by Biklen and Bogdana in 1977. In their terms disabled people are stereotyped as: pitiable and pathetic; objects of violence; sinister or evil; punishments for the sins of parents; atmosphere; supercrips; laughable; their own worst enemies; burdens; non-sexual; incapable of fully participating in everyday life (Rieser and Mason 1992:1998).

The supercrip is the 'hero of assimilation' (Riley, 2005:1), recognisable in *Susan's First Snowfall*, or in the disabled celebrity of Ade or Tanni. Given Dill's apparent inability to recognise this stereotype, I would suggest it is at least possible that during her fortnight's viewing Rose may have seen such images but did not consider them stereotypes. So heavily ingrained in cultural representation is this image as a positive representation of disabled people that its function in terms of invalidating the experience of impairment goes unnoticed.

Charles Riley asserts that 'traditional emphasis on the physical aspect renders the 'sadcrip-supercrip' two sides of the same coin' (Riley, 2005:4). While the narratives of pathetic victim and plucky struggler appear superficially to be doing different things they are part of a single discourse identifying impairment as tragedy. Before concluding this chapter I consider these two stereotypes along with a third, the 'unattractive and asexual' stereotype, in order to demonstrate the way in which, even in what are represented as being empowering and enlightened portrayals, stereotypes are currently used in popular culture to naturalise an oppressive way of thinking about disability.

The supercrip

Talking about his enjoyment of the TV coverage of the 2008 Paralympic Games, Ali says:

...it was just incredible, it was like... *woah, this is amazing*... and it was, like, *wow*... and you admire people like that, and you think... *wow, if someone could*... it makes you realize how lucky you are... to have those legs that other people might not have... and to think that they've put 110% into it while you're sitting at home...

eating and munching away... not going out running or whatever... you really admire people like that... (1.2:125ff.)

Ali's admiration for the determination of Paralympian athletes involves a comparison which recognises his own good fortune (*you realize how lucky you are... to have those legs that other people might not have...*) and engagement within disciplinary discourse around his own behaviour (*while you're sitting at home... eating and munching away... not going out running or whatever...*).

The association of the Paralympics with a triumph over tragedy narrative is reflected in the following statement from the Paralympics.com website:

Paralympians... are people who have overcome their disability and have gone on to represent their country at the highest level of disability and wheelchair sport (Paralympics.com, 2004: unpagged).

Praise and respect is given to those who have overcome 'their disability': *they have gone on to represent their country at the highest level*. Implied also is the insignificance of those who accept their impairments. The idea of the distinctness of 'the person' and 'the disability' or, in this case, 'the athlete' and 'the disability', as if the two can and should be considered separately, is repeated here:

While the Paralympics Games focus on the athlete, not the disability, spectators cannot help being inspired by the spirit of these talented men and women (Edgate, 2004: unpagged).

Impairment is to be overlooked, while the true heroism of the athlete is to be admired. Yet even so, we are reminded, it is difficult not to wonder at what these 'talented men and women' can do in spite of their afflictions. As spectacle, the Paralympics testify to the spirit of heroic individualism and make it difficult and confusing to think of disability as a structural relationship.

The endless regurgitation of a medical model view of disability, materialised at a cultural level through the recycling of the triumph over tragedy stereotype, is a highly effective way of ensuring that people with impairments reject impairment as a valid source of identity. Describing the term 'sports personality' as 'a contradiction in terms', Charles comments on his perception that, on those rare occasions when an actual disabled person is sought by the media to comment on disability issues, it is usually a disabled sportsperson:

think about it... if it was... say there was an international issue and a foreign country was coming to Britain for comment, you wouldn't ask a footballer, would you... you wouldn't ask any sports personality... you'd go to a politician or a writer or some other social commentator... and yet all we get are bloody... (1.2:562ff.)

Charles' point is that non-disabled sports personalities are not generally turned to for their sophisticated levels of insight on issues other than sport. Yet when it comes to disability, it is disabled sports stars who are asked for their thoughts.

Pathetic victims

Surinder discussed her portrayal in a number of newspaper photographs taken while she was involved in a 2006 media campaign for the MS Society. Considering a photograph which was printed three times in one edition of *The Glasgow Herald* (once in small detail on the front page, once in small and once in large detail on a later page), she exclaims:

Oh my goodness, he made me sit on the floor and ... and the way I'm sort ... the way I've got my hands on the black stick which is slanting ... erm ... and then my head is slanting ... er ... and it just all portrays the full image of *feel sorry for this person... feel sympathy for this person because it's* ... (1.2:24ff.)

The construction of Surinder's photographic image appears to have involved careful planning to ensure pathos. Surinder recalls her feelings of discomfort at the time the photo was taken:

I think the photo itself ... I mean, I remember it being taken at the time and thinking, I don't want you to do this... and I should have actually said that, I should have said no, I don't want to lean to one side, cos that leaning to one side... portrays an image of someone who's looking for...you know, I'm looking for pity ... (1.2:38ff.)

The text accompanying these photos gives a similarly bleak impression of Surinder's life:

For Surinder, even the simple task of filling her glass with water or chopping onion require enormous concentration and effort... negotiating a doorway often results in a bruise for the 38-year-old from Glasgow while a trip to the shops or a short walk along the beach can cause such fatigue that she becomes bedridden for several days...

While she accepts the basic facts described here, Surinder is annoyed by the tone in which they are written. The impression is conveyed, she feels, that her life experience is of relentless misery.

She draws attention to the story's headline:

I'm leading fight to help MS sufferers...

the word *sufferers* I would never use in my life... ever ever ever amen... connotations of suffering and negativity and in the ground... I don't see myself as a sufferer, so why on earth... and I didn't have any say in that again... if I'd known what the headline was going to be... I would have said excuse me, no... take that word out... it's inappropriate and it's not accurate... (1.2:365)

While Surinder is a confident, assertive, and vivacious Asian woman, *The Herald's* narrative depicts her as a sufferer whose life is blighted by tragedy. Elements of bravery are included here, in that 'in spite her of affliction', she still has the courage to lead the fight to help 'others as unfortunate as her'. She is not just to be pitied, but admired as well. The identity of sufferer is one that Surinder emphatically rejects. She muses ironically on the missed opportunity to raise some cash:

I mean, I could have had a begging bowl there and that would have been ...you know, the old term of handicapped and ...you know... I could have earned some money there... (1.2:221ff.)

The aim of this photograph and story is to produce an emotional response in *The Herald's* readers. In the careful manufacture of this image, in requiring that Surinder sat on the ground, the prominent placing of her walking stick, the poised angling of her head, we can regard in detail the imposition of the disabled role. In and through these instructions Surinder is turned from being an Asian woman who has MS into a disabled person. Those who buy and read *The Herald* are able to feel good about themselves because they have been reminded of their own good fortune in being able-bodied: unless, that is, they are disabled themselves, in which case they are reminded of how bleak their own lives are. More importantly, as far as *The Herald* is concerned, having been made to feel good about themselves today, its readers are sure to buy tomorrow's edition for more of this stuff. As Surinder puts it:

I've been used by the newspapers to make money... (1.2:394ff.)

William Stothers, who describes himself as ‘a middle-aged bearded and balding adult in a power-driven wheelchair’ (Stothers, 2009:38) says that, when he is in stores and shopping malls around each Christmas time, he gets a lot of smiles that are meant for Tiny Tim, the angelic disabled boy in Dickens’ *A Christmas Carol*. Anticipating being asked how he knows this, he replies:

People, mostly women but some men also, flash smiles at me. Not the kind of smiles most men would hope for from a woman, nor the neutral courtesy smile exchanged by strangers passing on the sidewalk, but that particularly precious smile that mixes compassion, condescension, and pity. It’s withering to the person on the receiving end (Stothers, 2009:38).

Popular cultural images stereotyping people with impairments as pathetic victims are not new. As Dickens’ 1843 London tale of Yuletide cheer still casts its shadow over the experience of a disabled American man 165 years afterwards, so these images of Surinder are new texts repeating the same trite message.

Unattractive and asexual

...the only sex scene that they had in it was quite distressing to watch... why is it distressing to watch... because people don’t think that disabled people have sex, when they do... so then you’re confused ... you’re a disabled person and you’re like... well, does that mean that people aren’t gonna want to have sex with me... and I saw that when I was like ... what... sixteen... eighteen... quite young ... and I thought ... that did have quite a strange sort of oh, my God... no-one’s ever gonna want to have sex with me... type-of-thing... ‘cos that was the only representation I’d seen, and it was like... fuck.... (1.2:1019ff.)

Sarah refers here to the bedroom scene in *Footprints in the Snow*, an ITV Sunday evening Family Drama broadcast in 2005. Starring Caroline Quentin and Kevin Whately, *Footprints* was a televised adaption of a disabled woman’s account of her experiences. Its plot is summarised as follows:

Paralysed from the waist down after a car crash, Julie Hill struggles to get used to her disability and to save her marriage. It looks as if her husband will leave her. Then doctors try a revolutionary treatment which feeds electrical impulses to her leg muscles - allowing her to ride a bicycle once again and so go out for bike rides with

her family. Her marriage survives and she and her husband end up closer together than before (Internet Movie Database, 2005: unpagged).

Charles identified *Footprints* as ‘an ITV sort of big effort to address disability rights’, adding that most disabled people he spoke with about it thought ‘it was just a big joke’ (1.2:382). This view, however, was not shared by non-disabled people he talked with about it, ‘people who weren’t aware of disability issues’, who ‘all thought it was marvellous’ (1.2:385). As a drama based on ‘a true story’ written by a disabled person, it was presented as progressive and claimed an authenticity that convinced many viewers that this was a genuine insight into the lives of disabled people. But, as Charles comments:

that doesn’t get rid of the fact that it went through all the stereotypes... literally all the stereotypes... I sat there ticking them off one by one... we’ve got asexual... pity, victim... chip on your shoulder...and then later on you get triumph over tragedy... quite comical... (1.2:384ff.)

Charles’ reaction to the sex scene was different to Sarah’s:

...when I first saw it I thought it was one of the funniest things...it’s the way she flops her leg over... and says *I can’t feel anything, but you might as well... it’s what you want...* ...it’s pretty revolting... isn’t it... you know... she’s not getting anything out of it... but she wants to do it because she wants to keep her husband... so that he’s satisfied... it’s just horrible... just the lighting... and the way it’s shot... and the fact that he’s... coming... and that she’s looking into the camera... I mean, it’s just, like... you know... it’s just revolting to watch... that he doesn’t really want to do it either... so neither of them want to do it... but they do it cos... you know... they’re trying to be normal... it’s horrific... (1.2:315ff.)

While the divergence in responses to the scene may in part be explained by the fact that Charles is no longer the sex-starved and sex-obsessed youth described in Chapter 4, neither found it pleasant. Sex with a disabled person is depicted as cold, grim and joyless.

As Sarah noted above, this is the only representation of disabled people having sex on TV that she has ever seen. She has experienced this as problematic because:

...you see sex on telly all the time with two able-bodied, normal people and you think ... oh ... that’s not relevant to me... and when you do see it involving disabled people, it’s not portrayed as a nice thing ... (1.2:1063ff.)

Opportunities for disabled people to use media representations as resources to draw on in exploring and constructing sexual identity, as part of an ongoing process of making sense of self – are, then, offered only in negative terms. While disabled sexuality is a subject that is almost always not represented, talked or thought about on TV, when it *is* portrayed it is as unpleasant, something neither disabled nor non-disabled people would wish for.

Conclusion

...well, interestingly in today's *Guardian*, there's a feature ... and this is quite interesting ... a prominent feature... erm... about a disabled woman choosing *not* to have ... erm ... amniocentesis ... but, counter-posed by that... which is an interesting article... is a huge spread ... I mean, bearing in mind that this is *The Guardian*, you know ... I think it's about seven pages on Britney Spears' descent into madness... (1.2:209ff.)

Mary's statement makes it clear that, in fact, disability rights issues *do* receive media coverage. We have seen this earlier in Charles' recollection of the discussion about Individual Budgets on *The Politics Show*. Yet, as Klobas has observed, for every story which shifts the focus to social issues disabled people face there are ten others reminding us that actually, after all, it is really all about the abnormality of individuals (Klobas, 1998). Britney's antics appear far more important and deserving of attention than the story of the disabled woman who has had the temerity to defy medical common sense.

Charles Riley argues that:

Nearly all the problems in the representation of people with disabilities can be traced to the imposition of the medical model on what would otherwise be compelling narratives (Riley, 2005:12).

As we considered the way in which Surinder was turned into a disabled person by *The Herald* photographer, we can see the imposition of the medical model in Lola's discussion of a radio comedy sketch recorded by her and a friend:

...you know me and Nancy did the thing for Radio Scotland... it ended up in *The Guardian* 'cos it was on Radio Scotland... but in *The Guardian* they didn't ... absolutely wouldn't put it even on the women's page... so it was firmly ... and it was about sex ... erm ... and they made up Nancy's impairment ... they made one up 'cos she refused to give one ... said that she had an ongoing degenerative disease

... which is complete bollocks....she got an apology ... a printed apology ...
(1.2:632ff.)

While the material in Lola and Nancy's sketch has been permitted to surface within media discourse, it has been carefully shunted onto *The Guardian's* health pages. Where Nancy refused to identify her impairment, an impairment has been ascribed to her. What we see here confirms Lodziak's remark on ideology within the media:

Most conceptions of the dominant ideology allow for the kind of flexibility which enables a range of alternative meanings to be incorporated in it (Lodziak, 1986:38).

When it is claimed that the media produces and reproduces a dominant ideology, it is understood that the dominant ideology itself embodies some ambiguity. While it is regarded as permissible, or even occasionally encouraged, to allow a social model perspective to be encountered within the terms of contemporary media discourse, it is important that this remains considered as but one of a plurality of perspectives rather than having any claim to truth status. Where the self is seen as a reflexive project, constantly undergoing change as it weighs up debates and contestations, the social model is treated as one narrative among many available to be chosen from. In opposition to the views of social modellists who regard medical and social models as fundamentally opposed ways of understanding disability (Drake, 1999:14), media culture encourages us to regard both as valid (though the infrequency with which the social model is considered ensures that its significance remains perceived as marginal). In Anthony Giddens' terms, whereas the politics of the personal uses lifestyle patterns as a means of addressing or combating oppression, the life politics promoted by the media does not primarily concern the conditions which liberate us in order to make choices: it is a politics which promotes choice for its own sake (Giddens, 2003:214/216).

Reflecting the structures of modern capitalism, media discourse endlessly promotes the primacy of the individual. While it is possible to talk in terms of a discourse which identifies disability as an unequal social relationship, so long as this remains as talk it need not trouble the way things 'just are'. In Ben's words:

The social model really doesn't get a look-in when it comes to media representation, does it, because the media is about... especially modern media... is about the media communicating to you as an individual... the media communicates to you individually... you don't get a sense that you're

part of society watching the television... you're one individual and it's a discourse between you and the box or YouTube or whatever... (1.2:514ff.)

It is important to recall that oppression within modern capitalism, whether experienced as disability by people with impairments or as false consciousness by the non-disabled, does not involve being 'helplessly manacled' (Fiske, 1995:169). There is much to be enjoyed in going with the flow. Taylor and Harris express this thought slightly differently: 'mass media audiences are not deceived into false consciousness but, rather, willingly participate and contrive at their own oppression' (Taylor and Harris, 2008:132).

I would argue that many disabled people, like most other people, find something about their current situations that makes them worth staying in. Ali suggests that:

Some people don't mind it, they go oh, we'll take advantage of that... and they don't mind the fact that people are feeling sorry for them... some people think hey, that's great... actually, I can give you an example... there was a lad who used to come in... and he was partially-sighted... he used to get c.d.s for free and he was just loving it... you know, hey, I can get this and that... I can take all these out... copy them and bring them back.... (1.2:217ff.)

Ben notes the high esteem in which disabled people who embrace the disabled role are held:

If you are a disabled person you're expected to contribute as much as anybody else... set an example in a way... disabled charity fund raisers... you see plenty of them in the newspapers... it used to be the most popular... it probably still is in newspapers... representation of local disabled people... they're the ones who get the OBEs and all of that... 'Brave So-and-So' was the typical one, always used to be in *The Coventry Evening Telegraph*... (1.2:293ff.)

In proposing an affirmative model which defines disability as a personal and social role imposed upon people with impairments, and in arguing that the media play a central part in reinforcing the expectations and relationships signified by this role, I am not suggesting a grand conspiracy by non-disabled people to oppress people with impairments. Participants within charity fund-raising events for disabled people believe that they are helping, just as many disabled people believe they are being helped. I would rather describe what is happening by borrowing Richard Hoggart's words:

It would be inflated to talk of a ‘conspiracy’ between broadcasters and their larger public here; ill-considered unaware complicity will do (Hoggart, 2005:67).

Hoggart contends that the reason why media producers don’t go in for serious critical analysis of the structural causes of human unhappiness is that they consider this would bore their consumers. On behalf of its audiences, the media occupies a role as a gatekeeper:

keeping out not so much obviously undesirable elements such as rank obscenity or malicious slander but worrying elements, elements which the anonymous audience simply ‘might not like’ – intellectual criticisms of some popular attitudes, anything remotely judgemental of those attitudes (Hoggart, 2005:71).

Broadcasters, celebrities, disabled people, all participate in the daily reproduction of disabling social relations because this seems right and because they cannot see how it could be different. If neither oppressors nor oppressed recognise their roles, but instead perceive the world as it is as the result of a natural ordering, it becomes difficult to name oppression. While everybody is absorbed with their own unique importance as individuals, as within a disciplinary society each is required to be, this naming becomes increasingly difficult.

Pierre Bourdieu muses:

Sometimes I want to go back over every word the television newspeople use, often without thinking and with no idea of the difficulty and the seriousness of the subjects they are talking about or the responsibilities they assume by talking about them in front of the thousands of people who watch the news without understanding what they see and without understanding that they don’t understand. Because these words do things, they make things – they create phantasms, fears, and phobias, or simply false representations (Bourdieu, 1998:20).

While Bourdieu refers here to newsreaders’ uses of words including *Islam*, *Islamic*, *Islamicist*, there are plenty of other words to which Bourdieu’s reflection could similarly be applied: *the disabled*, *people with disabilities*, *tragic*, *brave*, *triumph*, *struggling*, *suffering*, *overcoming*, *special*, *vulnerable*, *care*...

Chapter 7: Disability in Everyday Life

Introduction

Power is a thing of the senses... it lives as a capacity, or a yearning, or a festering resentment... it can begin as a secret kept or as a gesture glimpsed in a hallway (Stewart, 2007:84).

Kathleen Stewart describes ways in which ideology is materialised through what she terms 'the politics of ordinary affect'. While structures grow entrenched and identities take place within ways of knowing that have become habitual, she argues that ordinary affects give things the quality of a '*something to inhabit and animate*' (Stewart, 2007:15). In this way:

There's a politics to being/feeling connected (or not), to impacts that are shared (or not)... to all the forms of attunement and attachment. There's a politics to ways of watching and waiting for something to happen and to forms of agency... There's a politics to difference in itself... the difference of habit and dull routine, the difference of everything that matters (Stewart, 2007:16).

In my final chapter I describe and analyse a number of moments experienced by the participants in my research as they have been occupied in getting on with the business of everyday life: preparing an evening meal, going to a restaurant, looking for a pair of shoes to buy in Marks and Spencer, for example. While such moments may be ordinarily overlooked and regarded as insignificant, I argue that each is full of meaning. With Brett Farmer, I would suggest that 'it is precisely through the mundane and seemingly trivial practices of everyday life that ideology works most freely and effectively' (Farmer, 2003:22).

Susan Willis observes that 'almost everything we do in daily life, we do as individuals' (Willis, 1991:175), and it is as individuals that the politics of ordinary effect are experienced: where the words are heard and behaviours encountered which fix impaired individuals in the disabled role and remind them of the expectations implicit in that role. The majority of these observations were made with research participants as individuals: watching TV; crossing Birmingham New Street Railway Station; visiting an online chat room. Three participants asked if they could involve partners or friends as co-participants. Two participants I observed engaging interactively in work activities. I talked with each participant before and after each observation, usually by themselves but when asked I let other people join the conversations.

Joe Moran identifies 'the everyday' as a category that brings together lived culture and representation 'in a way that makes sense of, but also obscures, the reality of cultural change and social difference' (Moran, 2005:13). This change happens incessantly but without ever

seeming to. It is rapid, fleeting and unnoticeable, and takes place within the minutiae of everyday life even as what appears is an illusion of sameness. If public attitudes towards disabled people do change, they do so imperceptibly and between the cracks of obviousness, held back by dull resistance.

It is in the gestures, glances and tones of address experienced by disabled people that dominant social relations are shored up, for the words and internal conversations of the non-disabled with whom they interact are also informed by the same conventional narratives. While it may be far from their conscious intention, in making assumptions and judgements based on their cultural learning, the strangers, shop assistants, and waiters encountered by disabled people play a part in the ongoing production of unequal social relations, for, simultaneously, they project onto disabled people an understanding of what is perceived as their unfortunate difference and remind themselves of their own normality.

Themes

In this chapter I consider three themes emerging from the situations I observed and the discussions I held with participants about these situations. The first of these relates to the imposition of the disabled role. Initially I shall contrast two situations, both involving encounters with sales assistants. In the first situation the disabled role is imposed and in the second it is not. My intention here is not only to illustrate the way in which the role is imposed in everyday life situations, but also, by showing that it is not imposed within every encounter, to demonstrate the arbitrary and relational nature of disability. I follow this by discussing other illustrative examples.

My second theme relates to alienation. Here I discuss the situations of other people around participants in these everyday settings, illustrating that alienation is a part of human experience generally. My intention is to highlight the way in which, as a signifier of alienation, disability is a role imposed among other alienated roles.

I return to Markell's argument that:

human relationships based upon the subordination and denigration of certain social groups involve closing off some people's practical possibilities for the sake of other people's sense of mastery or invulnerability (Markell, 2003:23).

Within contexts of everyday life and of the politics of ordinary effect, the disabled role is imposed on people identified as having impairments by those considering themselves normal in order to reassure themselves that their own lives are tolerable. The sentiment that 'there is

always somebody worse off” naturalises, justifies and explains away unequal structural relations. While impairment is identified as misfortune the alienating constraints of normality seem bearable.

I am trying to convey here tensions experienced by people with impairments in identifying positively as people with impairments, in that even when an impaired individual interprets her own experience as valid, it is unlikely this view will be shared by those around her. A view which regards impairment positively will be regarded by most as incomprehensible.

Swain and French have argued that while many non-disabled people can readily accept the social model, even if only at a basic conceptual level (for example, they can accept that a wheelchair user unable to get into a building because of steps is disabled by environmental barriers) they are:

much more threatened and challenged by the notion that a wheelchair-user could be pleased and proud to be the person he or she is (Swain and French, 2000:570).

The idea of the desirable self is associated so deeply in contemporary culture with images of physical perfection – images aspired to but never achieved – that the idea that physical impairment can be considered other than as defect is perceived as unsettling. Where the self is equated with the surface which can be instantly evaluated, the idea that impairment can be considered desirable is considered preposterous. The condition of alienation is described in the parable told by the disabled philosopher Soren Kierkegaard about the peasant who bought new shoes:

It is related of a peasant who came to the Capital, and had made so much money that he could buy himself a pair of shoes and stockings and still had enough left over to get drunk on – it is related that as he was trying in his drunken state to find his way home he lay down in the middle of the highway and fell asleep. Then along came a wagon, and the driver shouted to him to move or he would run over his legs. Then the drunken peasant awoke, looked at his legs, and since by reason of the shoes and stockings he didn’t recognize them, he said to the driver, “Drive on, they are not my legs” (Kierkegaard, 1978:19).

Taken-for-granted ways of being within commodity capitalism tend to miss the importance of what really matters. Fitting in requires preoccupation with what we look like, what we wear, what we buy, what we consume, as markers of the self. Farmer expresses this differently but means much the same when he states that:

each subject internalises ideological conventions and imperatives, and then unconsciously uses these as regulatory yardsticks with which to measure and modify social identity and comportment (Farmer, 2003[b]:36).

The third theme I want to develop relates to the affirmation of self. From a social model view I would suggest that there are situations in everyday life, for example, on occasions when access requirements have been fully met, when people with impairments are not disabled; or, at least, are not being actively disabled. I have to be cautious here, for even at this point if an impaired person knows that he is likely once again to encounter barriers as soon as he moves into a different situation, he will or may still consider himself a disabled person. But given the right environment, good personal assistance if required, and the right company there are likely to be times when an impaired person can just be who they are and temporarily forget about disability.

The affirmation of self involves the pleasure that can be taken in the simple fact of being alive and unique – regardless of impairment and pain when these are present – and in valuing one's own life for its own sake. Relating this to my thesis I would argue that this is important because, whereas the social model concerns itself primarily with the exclusion of people with impairments from opportunities to participate as equals within capitalism, the affirmative model provides a tool with which to critique the values of capitalism. The requirement to be normal involves accepting a role necessary to participate in the ongoing business of accumulation. The validation of impairment as part of the self throws out a challenge to normalising discourses.

Michael de Certeau (1997) has characterised everyday life as a site in which tactics are employed in the multitude of minor points of resistance practiced by everyday people in their everyday lives. Private pleasures are snatched which defy and subvert the conditions by which lives are ordinarily constrained. In detailing some of the everyday pleasures enjoyed by the participants in my research, I illustrate the sense of enjoyment that can characterise disabled people's lives as much as anybody else's. Far from being an experience overshadowed by an ever-present awareness of personal tragedy, life with impairment is something that can be extremely satisfying.

Snapshots

Jack Levin (1996) uses the term 'sociological snapshots' to describe the ways in which the details of everyday life can be read as texts revealing the unceasing reproduction, transformation and stabilisation of social structural relations. While some of my observations

lasted several hours and others only an hour I shall not examine these in their wholeness but rather as snapshots highlighting, perhaps, something that happened in an instant or an encounter that took place over several minutes. I shall, however, give these snapshots context by explaining the scene within which they took place.

I have reproduced data which emerged in the midst of life, while in motion or in interaction with other people (as opposed to during interviews), in a tidied-up version of the note form I originally used to record them. This is intended to convey a sense of the animated rather than reflective context in which this data was produced.

Norbert Elias has argued that if we are concerned with the process of transformation of social structures, it is necessary to give attention to the ways in which, in the context of their experiences of social structures, people contribute both to their reproduction and their change (Elias, 1998:168). I have argued that we should regard disability as a role which upholds contemporary social relations of inequality. The structures which circumscribe everyday life and the institutions which uphold these structures may evolve and take different shape but always reflect the interests of the socially dominant. The experience of disabled people at the start of the second decade of the 21st century is changed and improved in many ways from the experience of thirty years ago, yet the role of disability within the capitalist edifice remains the same.

The disabled role

Rose: Shopping

Rose took me around the centre of the highland town where she lives to let me see some of the barriers she encounters as a wheelchair user whenever she comes shopping. She had some things she would have wanted to buy anyway and we agreed that as she went about her business of making purchases she would point out the barriers as she faced them. I should feel free, Rose told me, to note what I liked, including any interpersonal encounters. She showed me the restaurants she would like to go to but cannot get into (l.3:15ff.); the inaccessible cash machine and the wheelchair lift into the bank that has to be operated by a member of staff whose attention she has to attract from outside (l.3:48ff.); the hairdresser's she uses, not because it has a good reputation but because it has access to the basins (l.3:137ff.); the theatre which has an automatic door that is never switched on and a stair-lift she has to ride on while strangers walking up the stairs ask her if she is enjoying herself (l.3:165ff.); the unreachable high and low shelves in Woolworth's (l.256ff.); the inaccessible customer lift in the local department store (l.3:341ff.); and the difficult ramp at Costas coffee

that has to be charged at, so that people sitting by the window stare in fright, thinking that she is going to come crashing through (1.3:451ff.). We spoke with a number of shop assistants who were sympathetically apologetic that things weren't better and promised that improvements were being looked at.

We made a visit to W.H. Smith's. Rose had recently been given some W.H. Smith's vouchers as a birthday present and wanted to spend these on classical music. The music section in this shop is on the first floor. Rose found a sales assistant, a middle-aged woman probably slightly younger than herself.

"I'd like to buy some music," said Rose. "Can I use the lift?"

"Sorry," said the assistant. "We've been measured for a new lift but it's not been fitted yet."

"Can I use the service lift, then?"

"No," she said.

"I've got W.H. Smith's vouchers. Can I change them for cash, then?"

"No," said the assistant, "but I could go up and get a selection down."

"Do you have any Mozart?"

"We mostly do chart cd's," the assistant said.

We wait five minutes.

The assistant returns.

"Mozart's sold out," she said. "This is all the classical we've got."

She proffers a sad handful.

This encounter was one of inequality. While the sales assistant's initial apology may indicate an awkwardness or embarrassment about the lack of a customer lift, she is not prepared to consider Rose's suggestions of reasonable adjustments – using the service lift to get to the first floor or exchanging her WH Smith vouchers for money. Her suggestion that she herself goes upstairs and brings down a selection not only limits Rose's opportunity for browsing and enjoying taking the time to choose, part of the ordinary shopping experience, but makes a secret of what else lies upstairs. Whether or not Mozart is in stock is not the issue. In the music section on the first floor, had she been able to get there, Rose's eye might have been

caught by something else she wanted to listen to, something jazzy or bluesy. In Stewart's terms, there is a politics involved in Rose's having to wait downstairs. Dependence is created in that she is expected to make a choice from among those limited cd's the sales assistant brings back down with her. Some disabled people in this situation might feel a sense of obligation to buy: after all, the sales assistant has shown kindness in taking the trouble to go upstairs to fetch the classical cd's. As it happens, Rose is assertive enough to decline those she is offered.

The fact that, at the end of 2008, there was still no customer lift in W.H. Smith's in this highland town conveys several messages to Rose. It is not expected that people like her will want to come into this shop, certainly not to go upstairs, will not want to browse, will not want to choose, are not valued as customers. Here is a sense of disconnection, of difference as inferiority, from the majority of other shoppers. While presumably well-intentioned, the shop assistant's response to this situation is one which invalidates Rose's subject position while affirming her own: she can walk upstairs, Rose cannot.

Rose knows that she is experiencing inequality in this situation and it makes her feel uncomfortable. In having decided that she would like to examine the Mozart cd's for sale she identifies herself as a woman of discrimination and taste. Yet the power relationship involved in the encounter with the sales assistant is sensed as demeaning and belittling. Whereas she sees herself as an educated woman who enjoys classical music, she is cast here as someone who cannot climb the stairs, and as a victim of misfortune.

While she manages to maintain a positive view of herself, at an emotional level she finds this exhausting:

...it's the drip drip drip effect... it's when you have had that negative input not five times in a week but several times in a morning... in an afternoon... in an evening... it is about finding the resources to go on... (1.3:607ff.)

Rose recognises at an intellectual level that disability is a political issue:

...we know we need to do more about the pavements... we need to do more about the buses which aren't accessible... (1.3:622),

It is, however, at the level of the senses that she feels undermined not only by the condescending and patronising comments and responses she receives but also by those who, perhaps, mean well but still diminish her power and agency. In trying to preserve a positive self-identity, in many ways Rose rejects her disabled self.

...these are things I used to take for granted, I suppose, at one stage of my life... I can no longer participate in those events and so I shut them out... I don't want to watch other people doing them because it reminds me that I am unable to do that... and that's looking at it very widely... I'm not looking at the political or the strategic aspect of it, I'm talking about the emotional aspect of it... and I think that able-bodied people are very lucky... (1.3:646ff.)

Anne: Shopping

Among the shops I visited with Anne in Glasgow city centre was a travel agent in The Buchanan Galleries, a large shopping mall. Anne wanted to make enquiries about the cost of flight tickets to Melbourne, Australia, for January 2010. The Buchanan Galleries were full of Christmas shoppers. The travel agent was situated in a small booth, just off the main shopping area. We entered to find three very smart young workers in their twenties sat in a row behind a long counter. Beside each worker there was a computer. In front of the counter were three high seats. My own feeling was that these looked as if they had been designed to be uncomfortable, in order to minimise the length of time customers would want to sit on them, thereby keeping business brisk. As we entered, the young man behind the counter broke off conversation with his female colleagues and, smiling, turned to face us and invited us to sit. Anne did not explain to the sales assistant that she is deaf, though from her intonation this is clear. The young man seemed not to be thrown by this:

No hesitation

He listens

Asks questions

“How long are you thinking of going for?”

“Do you want to be there over Christmas?”

“I can't give precise costs yet, it's too far in advance”

“I'll look at October with Singapore Airlines”

“Stop in Singapore, Glasgow to London Heathrow,

London to Singapore, Singapore to Melbourne”

“At the moment you’re looking at £1170”

Anne is the only customer

My perception of this guy is he’s good

Not patronising

He is friendly, communicative, listening

Anne fires questions

He outlines options

“End of January we’ll have the contracts.”

“Take some brochures.”

“We can do you a round- the- world ticket so you can go both ways.”

(1.3:191ff.)

In our discussion later, Anne described her encounter with the sales assistant:

... interesting... helpful... straightforward... just the way I like it... what else can I say...he repeated himself when I asked him to... he also pointed out that he had an email address... he was fine, wasn’t he... so I’ll probably go back and book our flights there on the basis of his service... there’s really not an awful lot I can say... I expect other people to get over it fairly quickly and just to get on with it...

(1.3:476ff.)

In this instance, Anne was not disabled as the sales assistant took account of her impairment and met her needs by communicating clearly. What is illustrated here is that it is neither necessary nor inevitable that people with impairments will be disabled in every situation they encounter. Anne was met here with politeness and respect. It is not that she was *allowed* to be a deaf person – as if something extra was required of the sales assistant – but that her deafness was not made an issue.

Ali, Ash, Sarah, Surinder: Watching Telly

Carol Thomas has observed that the agents or ‘carriers’ of disablism include not only those close to us or others we come into contact with, but also ‘unknown individuals and disembodied others in the media and wider culture’ (Thomas, 1999:48). With this in mind, I watched an episode of the popular Channel 4 game show *Deal Or No Deal* with four participants, Ali, Ash, Sarah and Surinder. I watched the same episode with each of them separately and in their own homes in order to recreate approximately the context in which each normally watches television – at home, alone. I had ascertained with each prior to our viewing that each watches *Deal Or No Deal* anyway: this was not a novel experience.

Deal Or No Deal is presented by ‘TV personality’ Noel Edmonds. Each afternoon one player from among 22 is selected to play the game. The others watch and cheer and remain in position with their boxes, offering encouragement to the selected player and hoping that their turn will come soon. Each player has a red box containing an unknown cash prize ranging in value from 1p. to £250,000. The selected player must choose boxes randomly with the hope of maximising the sum of prize money she will be offered. The tension of the game is built around the player having periodically to consider prize offers and to judge whether to ‘Deal’ for the amount currently on offer or to ‘No Deal’, gambling and taking the chance of a lower or higher offer after playing the next round. The cash offers are made by a mystery figure on the unseen end of a telephone line known as the Banker. Edmonds chats on the telephone with the Banker before presenting the cash prize offers to the player. He also encourages emotional audience participation throughout the game.

The contestant playing to see if he could win ‘life-changing money’ on the show I watched with Ali, Ash, Sarah and Surinder was Rhys, a young man from Wales, who is a wheelchair user. We watched the episode on a dvd sent by Channel 4 for my use in this research. I asked each participant to pause the transmission whenever he or she wanted to talk about their thoughts on what was unfolding within the programme.

Straight In

Noel: *Welcome... Rhys Devereaux... from Llanelli... Mum’s here... hello, Betty... tell me about Friedrich’s ataxia...*

Rhys: *Well, I suffer from Friedrich’s ataxia which is a genetic condition...*

The camera has already focussed upon Rhys's mother in the audience. Rhys has hardly had time to settle himself before Edmonds is straight in:

Noel: *Tell me about Friedrich's ataxia.*

We find ourselves drawn into a description of Rhys's medical condition. Almost every piece of cultural learning about impairment and disability the viewer has brought to this point is confirmed. Impairment is the most significant characteristic defining disabled people's lives. Disability can only be suffered.

Sarah remarked:

Why does that need to be the first thing that they go into... and I also think it's a bit weird that his mum's there... everybody else takes a partner or a friend... and he's got his mum and it just lives up to the stereotype... like they normally say who they're with... like a partner or whoever... and then they talk about what they want to win... what their ambition is... but the first one with him is like his disability... (1.3:23ff.)

Surinder suggested it is unlikely that Edmonds would turn to another contestant and demand they tell him about being black; about being gay; about being old (1.3:32ff.).

Personal Tragedy

Ali (1.3:99) noticed the sympathetic faces of the studio audience as they are panned by the camera while Rhys describes his situation:

...my mobility started getting worse and worse... then after university I started using the wheelchair... after having some problems with my heart...

It is as if 'it's the end of the world', Ali said (1.3:109), while Surinder noted that:

the camera is now going onto contestants... and their heads are leaning down... some of them look as though they've got tears in their eyes... it looks as if they're going *oh... poor, poor guy...* one of the girls... she's wearing yellow... head slanted to one side as if to say *aw... that's such a shame...* (1.3:71ff.)

Sarah observed that:

He looks like he's gonna cry... he sounds like he's about to cry and it's like... and also he totally bypasses... yeah, he went to university, so he's achieved stuff... but

that doesn't seem to be as important as the disability... what's your ambition... what's your life about... what do you do... what did he study at uni... those would be the kind of questions I'd be asking... but then you don't know... you don't know if that's like why the programme picked him... (1.3:37ff.)

Ash had few doubts about why Rhys has been picked for the programme. Rhys is a good-looking young man, this adding to the cruelty of his affliction:

He's articulate... he's just what everybody wants a disabled person to be like... well, from the top he looks just like... what everybody wants to think a disabled person's like... (1.3:115ff.)

How much more tragic it is that someone as young and attractive as Rhys has had his life struck down than had it been somebody from whom the audience might recoil.

If we had never heard of Friedrich's ataxia before this episode, we certainly will have by the end of it: not just about the devastating impact of the condition, but about the astonishing bravery of young Rhys as a sufferer. We have it all here: tragedy, pathos, suffering, overcoming.

Noel: *But you have decided to take a very positive attitude to this...*

Rhys: *I'm not going to sit down and just let the condition get worse and worse... I'm going to fight and give my all to get better...*

Surinder laughed.

Noel: *Would I be right in thinking that your ambition for this game... the object of winning as much money as possible... it is to be able to have more treatment...*

Rhys: *Yeah... this is going to take a long stretch of perseverance and just determination...*

Sarah sniggered.

Noel: *Perseverance... determination... pure guts... and regrettably, because of the world in which we live... money...*

Invalidation of the disabled subject position

It becomes clear that Rhys has come onto *Deal Or No Deal* to win as much money as possible so he can pay for the medical treatment which will cure him.

Given that Cumberbatch and Negrine's 1992 *Images of Disability on Television* report states that not one of 44 game shows watched contained a disabled contestant (Cumberbatch and Negrine, 1992), it might be argued that it is good to see more disabled people on programmes like *Deal Or No Deal*. The cultural message being broadcast, however, is far from suggesting that impairment is a valid experience. Rhys is being exhibited as a cripple with the right attitude, as somebody who will not just passively accept his lot. This is not just entertainment, but a valuable learning experience.

As Sarah remarked:

perseverance, determination and guts... they're all the words that are associated with being disabled... cos you've got to live up to that and if you don't live up to that then you're not... you're not striving to be better... and it pisses me off... cos sometimes it's okay just to be like... you know what... I'm happy living my life the way I live it... if you say that people are like oh, you gave up... gave up what... because I'm happy with my situation... this programme... it's like seen to be changing people's lives... but it's like changing what some people would never be able to change... so they might sit and watch this and go so if I'm not striving to like get treatment... if I don't think like that then what... am I less of a person... (1.3.283ff.)

Ash's prediction that we would hear the word 'inspiration' was soon fulfilled. Opening box number 7, fellow contestant Leon said:

You've been an inspiration, Rhys, you really have...

As Ash put it:

What's he done... he's just sat there... how can he be an inspiration... they dinnae know what he does... they never asked what he does during the week... he probably does some voluntary work or something... he's just sat there and spoke... (1.3:314ff.)

Another contestant, Sandie, opening box 12, made a statement presumably intended to encourage:

The Rhys I've met will walk again...

Sarah wondered what this tells people.

I think it's really confusing if you're like... young and you're trying to work out what you feel about these things... if that's all you're seeing... (1.3:406ff.)

This restitution narrative runs throughout the programme. Having ‘dealt’ at £20,000, Rhys commented that:

The treatment I’m having costs a fair bit and that’ll keep me going for a long time... and hopefully by the time it runs out I’ll be walking and doing everything as a normal person would... so... I’ll get there eventually, it’s just this is going to really help to speed up the process...

It is, Sarah noted, the constant repetition of this aspiration to normality (1.3:421).

Surinder wanted to hurl the remote control. She commented that:

I’ve never actually broken a TV before, but I’m getting there... (1.3:313).

It is, Ash considered, false hope (1.3:409).

Yet Edmonds’ words *Fantastic... fantastic...* endorse this false hope. Rhys’s fellow contestants are inspired by this false hope. The studio audience, *the pilgrims* as Edmonds calls them, sanctify this false hope.

Rhys was told by Edmonds that:

You will have inspired hundreds, probably thousands of people you will probably never meet...

Finally, as Rhys is congratulated on his winnings by his fellow contestants, Noel faces the camera, wipes his eye, and says:

And we’ve done it again... you’re a hard-hearted person if you didn’t have a little bit of a twitch then when Sandie said you will walk again... this guy’s got serious courage... and he’s now got twenty thousand pounds to get that special treatment he needs...

Sarah was relieved that the show had come to an end:

Thank God it’s finished... it’s painful... it’s painful to watch... it’s so stupid... it makes you feel quite depressed when I watch that cos it’s... he obviously feels that crap about the situation that he’s got to make himself better... but... I have to keep reminding myself... it’s not something that I need to aspire to... (1.3:454ff.)

What's going on?

Emma Bowler recently cited *Deal Or No Deal* as a positive example of TV's increasing incidental inclusion of disabled people (Bowler, 2009: unpagged). Having watched Rhys's Game more times than I care to remember I have to question whether this is really progress. Rather I would argue that Edmonds, Rhys, the studio audience including his mother, and the other contestants, are actively involved in reinforcing the cultural myth that disabled people are tragic victims.

Speaking of Leon, who described Rhys as an inspiration, Ali said:

you can argue about that guy who says that... he's just any old guy... they're just naive and say stupid things... I think it's just a crock of shite coming out his mouth... I don't blame him because he's not... it's like he hasn't been brought up in a world where... he probably hasn't been around that many people who are disabled... it's just like his way of going *oh well... you're not like me, so...* I don't blame him in a sense because he's not been brought up around people who are disabled... (1.3:292ff.)

While Young has stated that relations of structural oppression between social groups do not always fit the paradigm of conscious and intentional oppression of one group by another, she emphasises that she is not denying that specific groups are beneficiaries of the oppression of other groups and thus have an interest in their continued oppression (Young, 1990:41).

While Leon, Sandie, or any of the other participants surrounding Rhys in *Deal Or No Deal* may not regard themselves as actively re-enacting and materialising disabling social relations within popular culture, this is what is happening. In celebrating Rhys's rejection of impairment as a valid life experience or basis for identity, they reaffirm their own normality. Rhys performs the disabled role in his rejection of impairment as something there is anything to be gained from. He is confirmed in this role both in the pitying glances and in the praise he receives for his determination to be cured.

Sarah remarked that:

You're constantly like reminded of the treatment element there... it's always... it creeps back in... when you think they might actually move away from it, it creeps back in... and I think that's like... him... but for the audience as well... it's like constantly reminding them this is what this person's about... (1.3:394ff.)

My intention in watching this episode with Ali, Ash, Sarah and Surinder was to try and explore their reactions to cultural representations of disabled people that might be experienced in the course of everyday life. This is the sort of cultural material that anybody, disabled or non-disabled, might sit down to enjoy of an afternoon, or on one of the many repeats on different channels (Channel 4+1, More 4) and will generally be viewed uncritically. As Sarah notes:

...the vast majority of people sitting watching this won't be thinking that's annoying... they'll be thinking it's good... (1.3:383ff.)

Her perception is that it is likely that this episode of *Deal Or No Deal* will have been watched positively and regarded as a good example of greater inclusion of disabled people in TV programming. Yet, at the same time, it is possible to hear caution being expressed. For example, Ash states that:

It's good that he's on... it's good that the chap's on... it's more important that he's on than that he's no... I think anybody would agree with that... to show people... (1.3:223ff.)

Sarah is torn. She feels instinctively that increased representation of disabled people on TV is desirable, but is concerned about the message being put out:

Any representation, I suppose, is good... but I would hate to think that people would like look at that and think that every disabled person is like that and should be thinking like that... to be honest, *Deal Or No Deal's* probably the most representative in terms of disability... so I think *Deal Or No Deal's* probably better than most... in terms of the amount... but whether it's the right kind of representation I don't know... (1.3:192ff.)

While it is true that disabled people have long argued for greater representation in mainstream media, it is also true that popular culture has a way of assimilating challenges to its ongoing flow by incorporating them and offering them back for public consumption in a form in which they are likely to cause little disruption or offence (Chambers, 1993).

The confusion and oppression experienced by many disabled people in relation to feeling comfortable in their own bodies is expressed by Sarah, referring here to Rhys:

It's only ever either one way or the other... there's sort of the timid... like him... or there's the angry... like I'm thinking back to *Beyond Boundaries*... where there's

characters in that that were really angry... so it's from one extreme to the other and if you don't fit in to either then you're like is there something wrong with me... like I'm happy with my situation and I'm happy with the level of ability that I've got... I'm still ambitious but it's not ambitious to be like better in terms of my disability... I'm just ambitious to do things with my life... and be successful... my wheelchair really doesn't come into it... but I feel on telly it's not represented that way... (1.341ff.)

In highlighting the two positions on disability she feels are portrayed within mainstream media, Sarah draws us back to the two positions I have identified as describing the disabled role. The first is the role played by Rhys, of accepting his own inferiority until he is cured: the second is a position which tries to transcend impairment and its significance through superhuman effort.

As a young disabled adult who watches television as part of everyday life, Sarah expresses succinctly the tensions experienced by many disabled people who would like to enjoy being who they are, but are made to feel that this is unrealistic.

Kevin: Looking out of a window

...there's a bike going past... Gizzy... woof... too late, it's gone... (1.3.128)

Michael de Certeau suggests there is a peculiar mix of freedom and imprisonment in the act of gazing out of the window on a train journey, a melancholic pleasure 'of seeing what one is separated from' (Certeau, 1997:114). I suggest also that Kevin's glimpse of a cyclist's lamp passing his cottage on a dark night confirms both a sense of possibility – the cyclist is, at least, going *somewhere else* – and reminds him of his isolation. He calls Gizmo, his fat Yorkshire terrier, to share the momentary fellowship. At least another soul has been near.

I talked with Kevin as he prepared his evening meal during a cold mid-December evening some forty miles north of Aberdeen. He lives in a former fisherman's cottage a stone's throw from the North Sea. We had originally arranged that I would accompany him on his walk to the Co-Operative store in the nearby town of Fraserburgh. Events, however, had prevented this from happening. A delay in my train journey together with Kevin's concern about the oncoming darkness meant that by the time I arrived he had already been and returned from town. So, instead, I talked with him as he prepared his evening meal. I talked with him about some of the objects in the room.

Sherry Turkle has described ways in which objects can be considered ‘as companions to our emotional lives or as provocations to thought’, and regarded ‘as connections to lives past and experienced as part of the self, able to catalyse self-creation’ (Turkle, 2007:9). My thinking was that, among the clutter and untidiness in which he spends his life, there might be things – cards or photographs on the wall, for instance - upon which his attention will sometimes focus, drawing him back into remembrance of people, places, times. This seemed like a promising way of gaining insight into Kevin’s private narratives – in order to consider these against the assumption that disabled people’s thoughts and experiences are overshadowed by the fact of impairment.

I had originally hoped to observe Kevin during some form of social interaction, which was why the visit to the shop had seemed a good idea. He had commented in our first interview that:

I’ve come to accept that I don’t care what people think about me... and I’ve got a trolley in the shed... I put two pieces of wood on it... and a carpet on top... Gizmo stands on the front... and I take it into town every time I go shopping, because I can’t carry the shopping... so I walk around the town... and I think what the hell must people be thinking of me... but... well, what can I do... I can’t carry the shopping to the bus stop... because it’s too far to walk... too heavy... and I don’t want to go too often... because going to town... and back... is just about it for me... (l.1:534ff.)

I had wondered whether there is a connection for disabled people between coming to accept that they ‘don’t care what other people think’ and coming to regard themselves positively. I had wanted to reflect on whether Kevin’s use of the trolley involves a pragmatic recognition and ownership of his own needs and an enacted demand of the right to do things differently, or simply resignation. But, as my primary intention was to observe him at some mundane activity, cooking the tea would serve just as well.

With the exception of the women in the Co-Operative when he visits town, Kevin rarely talks to other people. I got the impression that he receives few visitors and rarely visits anyone. Most of the people he talked about during our conversations – his mother, his ex-wives, a few ex-neighbours – live in the south of England. Kevin moved to this cottage about five or six years ago because it was the only property in Britain he could find on the Internet that he could afford to buy.

While he described himself as taking ‘a lot of interest in sexual things, you know... I’m very much interested in that line’ (1.3:131), Kevin does not believe that any woman would be interested in him:

I could never bring her back here... personally I don’t think anyone would be interested... basically cos of where I live... you know, if I was to go out with a girl obviously I’d get myself spick and span... do all the things necessary... but I couldn’t bring her back here... because it’s just me I don’t care how filthy I get... how filthy things get... you know... (1.3:130ff.)

In spite of the way in which it could be considered that Kevin has isolated himself, his appreciation of companionship was expressed while talking of his fondness for Gizmo:

...just to see him doing what he’s doing now... scratching the cardboard... that’s what I call company... it’s nice... otherwise, if it wasn’t that what would there be... silence... (1.3:65ff.)

He spoke about the way in which Gizmo keeps him alert to anyone passing the cottage:

I know when this person walks along the road past the house cos he has a little woof... and I stand by the window and say *there he goes... there he goes...* and he gets all excited... (1.3:13ff.)

In considering Kevin standing at his window, watching as the occasional stranger passes by, we can see another example of the disabled role being played out. In this situation, the disabled role is not being actively imposed, for it does not need to be.

Kevin had the disabled role imposed on him early in life at the residential school he was sent to. Until this happened he had been a sensitive, shy, intelligent, asthmatic boy who had been doing well at his lessons. At residential school in the middle of rural Surrey he missed out on gaining the ordinary emotional experiences and skills necessary to become a competent social performer, comfortable around other people and in his own skin.

Removed from the social mainstream, he describes his experience of adolescence as ‘insular’ (1.3:674), characterised by minor sexual abuse from other boys (1.3:604ff.), lack of formal education (1.3:636), poor adult guidance (1.3:670ff.); nicking Action Man figures from Woolworth’s on weekend visits to Guildford (1.3:519); and acute embarrassment in the company of girls (1.3:544). By the time he was re-admitted to the mainstream on leaving school he was ill prepared for adulthood. Little was expected of him.

While Kevin stands at his kitchen window, calling his dog to notice with him as somebody else passes by outside, I gain a sense that he has taken upon himself the responsibility of withdrawing again from the mainstream, of admitting that he has no real place in society. There are plenty of people who withdraw from the mainstream as a positive lifestyle choice, but in Kevin's situation I see this as a sign involving acceptance of defeat:

I've never really thought that my brain was strong enough to withstand the pressures of life, really... (1.3:657)

This is not to say that Kevin is particularly unhappy about his situation. He told me of many things that he loves about living where he does, including the light nights and the beach walks in the summer; the seals, the cormorants and the herons; the peace and quiet. Yet I sense he is a person who has experienced a lot of hurt. Not all people resist the roles given to them. Some see no other way of being.

...one thing I do is I keep an eye on the clock for television... I'm a *Strictly Come Dancing* fan... and every night at six thirty *Strictly Come Dancing Take 2* is on... (1.3:146ff.)

During the long, dark evenings of the remote north Aberdeenshire winter, Kevin spends a lot of time watching TV. There will be millions, too, living far more closely to each other who will spend their time doing exactly the same: alone even while in the presence of those nearest to them. While roles may differ, escape from alienation is hard.

Mary: Waiting

...when I was waiting for you in the tube station last night, this guy just comes up to me and says... *you're at Chalk Farm Tube Station*... (1.3:837ff.)

I had arranged to meet Mary and her partner Donald in London. Mary and Donald were in London on trade union business and I had been delivering a lecture at London Metropolitan University. It had been planned we should go for a meal together, but it turned out Mary had forgotten this and had (unexpectedly and very kindly) prepared a meal instead. We met again the following morning, before Donald headed back to Dundee, and went out for a coffee, intending this to be the focus of my discussion.

Reflecting on my notes and interview transcripts, however, rather than reflecting principally upon our visit to the Salvation Army cafe at Haverstock Hill, I want to consider an encounter

experienced by Donald as he waited to meet me at Chalk Farm tube station the previous evening.

It is worth noting, however, that the decision to go to the Salvation Army cafe was made not because this was somewhere Mary and Donald especially fancied, but for access reasons. In other words, it looked more accessible than the other nearby cafe we considered. Mary remarked:

...by choice, I probably wouldn't have chosen to give my money to the Salvation Army... however... I ... they have £1.80 which they earned because... they looked a bit more accessible than the... more upmarket café down the road ... (1.3:871ff.)

She described what is often experienced as the ordeal involved in going to places where a cup of decent coffee rather than a cup of instant is guaranteed:

...it's barrier stuff, isn't it... depending on the staff attitudes... how helpful they are... depending on the boards and how they're written... where they're placed, you know... these kind of things... how busy it is, getting the stuff back to the table, you know... these kind of things which I think *needn't* be a problem but usually are... (1.3:257ff.)

On this occasion they settled for the Salvation Army cafe:

this is comparatively less stressful

costa and starbucks are dreadful

they do nice coffee which I like

but it's a very stressful experience

we chose the Salvation Army because it's quieter

(1.3:15ff.)

Discussing the scene after Donald had left, Mary recalled of the interaction with the volunteer serving in the cafe:

The guy was okay ... you know... but, erm ... I don't know what he would have been like if it had have been busier ... I don't know ... but he was all right... but he didn't... he wasn't required to do anything, except serve us... I don't have to ask him

anything because the ... er... the... er ... the... the number of things that you can choose here is probably pretty limited anyway... so we didn't present anything like a challenge to him ... so ... he seems an okay guy... (1.3:876ff.)

Beyond the limited choice of accessible places to go, the business of going out for a coffee was, on this occasion, relatively hassle-free. But the issue seems to be not whether or not being placed within the disabled role occurred on this specific occasion so much as the constant tension involved in experiencing this as something which *might* happen. In Mary's experience as a partially-sighted woman this shapes decisions that have to be made every time she enters a public place. There arises an issue of whether or not she should hide or display her cane:

everybody wants a semblance of control

if I had my cane I'm more likely to be actively patronised

do I draw attention to my impairment or not

you're made to feel a nuisance

(1.3:6ff.)

If her cane is folded away in her handbag it is likely that her impairment will not be noticed and she will be treated normally. However, she will then have to deal with the stress involved in passing as a sighted person to get what she wants. She has learned that displaying her cane often leads to being treated as incompetent.

The previous evening Donald had gone to Chalk Farm tube station to await my arrival. Donald is blind, and had been standing at the entrance smoking a cigarette when a stranger, presumably passing in or out, stopped and told him "You're at Chalk Farm tube station" (1.3:837).

Donald contends that disabled people see the world 'at its most stupid' (1.3:447ff.) How, he wondered, did this man presume he manages the rest of the time, without people there to point out the obvious? (1.3:838) I suggest that this incident gives a clear illustration of the imposition of the disabled role. Donald's private thoughts as he awaited my arrival and smoked his cigarette could have ranged across a whole range of areas:

When's Colin going to show up... how's the rail strike going to be resolved... why's City Airport so fucking inaccessible... I'll not see Mary for another six days after I

get back to Dundee... will Angus be able to get to the meeting... I've got itchy balls but I can't really scratch them here...

I don't have access to Donald's private thoughts, but I would suggest that it is more likely that these, or similar, rather than his blindness would have been the objects of his meditations. Yet from out of nowhere the disabled role is imposed on him once again by a stranger he cannot see, who speaks to him and walks away. The fact of his blindness is pointed out to him. He is reminded that he is perceived by others as the victim of a 'woeful affliction' (Klages, M. 1999). The difficulty in knowing instantaneously how to respond to such an unexpected intrusion is reflected in Donald's words:

You know he's trying to be helpful and I know it wasn't malicious and it wasn't nasty ... and I wasn't rude to him and I did say *thanks*... (1.3:842ff.)

There was much laughter at this comment, from Donald himself, from Mary and from me.

Alienation

Hazel: Shopping

I accompanied Hazel as she went to buy a pair of shoes in Abington Street in Northampton. It was a mild, grey mid-November Friday morning. The town seemed busy, full of people. I waited for Hazel on a bench opposite Marks and Spencer. A Santa's grotto had been set up nearby and the tune of *Jingle Bells* could be heard playing.

I wanted to consider with Hazel the absence of images of people with impairments as we passed along Abington Street and through the shops. I wanted to discuss with her the possibility that the invisibility of disabled people in marketing and advertising played a part in her own reluctance to identify as disabled. If people with impairments are almost never seen in commercial depictions of desirability, did she feel that at some level this could be involved in shaping her reservations about disclosing to others details of her condition? At what cost is an outward appearance of normality bought?

During our initial discussion in Jenny's Cafe, Hazel questioned my reading of photographic and televised images, mannequins and displays in high street shops as reinforcing assumptions about the attractiveness of normality. I had suggested that the absence of impairment might be saying something about impairment.

I have a different view as to what you said about images of normality... because I look at those images often and think they're images of perfection... so I suppose... normality... I don't see it like that because I don't think they are normal people... there are some nice good-looking women that are size 10... ideal looks... everything in the right place and all of that... but I don't see those images as being normal... I see them as being... the perfection that a lot of people try to strive for... but I don't consider them as normal... (1.643ff.)

Hazel's challenge set me upon a new line of thinking. Audrey Yue discusses the techniques of intoxicating distraction practiced by department stores, the construction of consumer identity through exchanges of looks, the use of glass and mirrors reflecting and multiplying displays while at the same time making the shopper more self-aware of her presence in the space, seduced by the sight of her own literal reflection and constituted as a self-conscious subject of consumption (Yue, 2003:128). The surrounding images of models – glamorous, successful, sexy, enjoying themselves – awaken a sense of inadequacy in the typical Northampton shopper which will only be temporarily assuaged by buying into this line, this brand, this fashion, this dream.

Hazel reflected on the display mannequins in Marks and Spencer's windows:

It's about perfection and it's unrealistic... if you're 5 foot 10 inches tall, with all your curves in the right places come in here and you can look great... that dress might look great on that mannequin, but it wouldn't in my size... (1.3:52ff.)

Inside the shop, Hazel muses sadly as she contemplates the section where they display the shoes she would actually want to buy:

I'd still love to wear dainty glamorous shoes like that, but if you want to look good in the M and S brand, you've got to be a certain size... they don't cater for people like me... (1.3:217ff.)

It is at this point that Hazel tells me about the short time she spent as a wheelchair-user during her teens.

I had
an operation
in my teens

my feet
were broken
I spent three
months in a
wheelchair
look at the
mannequin's
dainty shoes
mine are
like an
elephant's
a lot of
women like
nice lovely
shoes
it's really
horrible and
upsetting
if I want to
buy a nice
pair of shoes
I have to
go out

and spend
a lot of
money
I might
try shoes
on in
here but
I'll put
them back
on the
shelf
I won't
try them
because I
don't want
to show
my feet
and scars
particularly
in summer
sometimes
I feel
that people

are looking

maybe

they're not

but I feel

self-conscious

(1.3:84ff.)

I found myself wondering why she has not mentioned this before, especially during our first conversation. I speculate on Hazel's internalised oppression, but I have a feeling this is something I would not be able to easily draw out from her. I do not want to come across as too intrusive.

Hazel decided to buy a pair of slippers and a bottle of nice wine instead. I had offered £30 from my research budget in order to make the shopping visit authentic and, quite rightly, she intended spending it.

Hazel's long-term condition – or possibly the medication she is prescribed to control her condition - means that her weight fluctuates. She has an ungovernable body or, at least, a body that is not willingly or easily made to conform to the shape and size that contemporary fashion requires. She is far from being hideously fat or unattractive, but she sometimes feels both. Her condition means the disciplinary practices required to maintain her ideal figure – or Marks and Spencer's ideal figure – cannot be relied upon to produce the desired effect.

Hazel does not consider herself disabled. While she recognises her impairment, she describes herself as 'an able-bodied person' (1.3:741). Describing a recent experience visiting her g.p. when she had felt belittled by the nurse, she expressed concern that:

if she's treating an able-bodied person like that it would worry me about how she would treat someone with perhaps another disability... (1.3:743)

I believe there was validity in both my own reading that advertising images are used to sell normality and in Hazel's alternative suggestion that these images relate to perfection. While cultural signs can be read in innumerable ways and situated within different discourses and sets of practices (Bowman, 2008), I think there is something aligning our two trains of thought.

This can perhaps be understood by considering Lennard Davis' description of 'the normal ideal body':

The normal ideal body is the one we see on the screen. It is the commodified body of the eroticised male or female star. This body is not actually the norm, but it is the fantasized, hypostasized body of commodified desire (Davis, 1995:154).

While Davis describes big screen representations, I suggest we can use 'the normal ideal body' to describe the bodies we see modelling the latest designs plastered on the walls of high street clothes shops. While these are not the bodies of 'real people' (hence the shopper's feelings of inadequacy when measuring herself against them) but an idealised version, they must be recognisable as close enough to the norm otherwise the illusion of attaining this ideal would be revealed as a falsehood. The perpetual personal investment of consumers in this illusion must be secured so that they keep on purchasing. The impaired body has no role other than as something negative against which the normal body evaluates its own image.

After we left Marks and Spencer's, Hazel and I continued our search for slippers in British Home Stores. Here Hazel found a pair that she liked and made her purchase. On our way out of the shop, I made a note of what I saw:

a woman at the door shakes a bucket for *Children in Need* while, with her other hand, she gives out flyers that say *BHS an extra 20% off EVERYTHING*

I am not sure I have ever seen such a literal entwining of the symbols of charity and commerce. The bucket held by the one hand offered shoppers the opportunity to remind themselves of their own blessedness. The flyers handed out by the other encouraged them to invest further within a system which always fails to satisfy.

I do not know whether the woman was being paid or was doing this voluntarily. The fact that she was handing out promotional flyers for British Home Stores makes me hope that she was being remunerated. On the other hand, if she was a member of BHS staff the ploy of using *Children in Need* to promote a sale indicates extreme cynicism. Either way, while she shook her bucket on behalf of those she presumably considers less fortunate, her own position appeared absurd.

Brian: 50th Birthday Party

Head into Brighton

Bus from Brunswick Square to North Street

Crowds heaving

Night buzzing

Still hot

Young people

Undercurrent of violence

Pissed women wearing little

Pissed men on the pull

We find a table

Sit with pints

Too loud to talk

Unless you shout

All around the question is asked:

“Where’s the good time?”

(1.3:175ff.)

From around 2pm during the glorious late July afternoon, around forty guests made up of family and friends - older people, children and teenagers, disabled friends and colleagues, non-disabled friends from back in the days in the early 80s when you could rent a room in Tottenham for £6 a week – turned up for Brian’s 50th birthday party. This took place outdoors in a park near his Hove flat. There were camping chairs, rugs, blankets and a fabulous spread laid out: sandwiches, grapes, strawberries, sausage rolls, pork pies, tomatoes, pizza, crisps, bottled beers, fruit scones, fancy cakes, cucumber slices, mini sausages, chiplets. Old friends were greeted, presents and cards given, and a birthday cake was produced with fifty candles for Brian to blow out while everybody sang ‘Happy birthday’. The portable c.d. player belted out Ian Dury, and later Sinéad O’Connor.

Speaking about the party afterwards, Brian recalled:

Well, it was fab... it was (*sighs*)... a lot of fun... people from all different times and areas of my... of my life and er ... it was a very nice atmosphere, you know... it was just ... made loads of food, put it out there and let everybody get on with it really and er... the weather was just absolutely perfect and it was just very chilled out and er... a warm, sunny time ... just a real privilege to be able to share some time with... er ... you know, people who've been very dear to me at different times in my life through my... (1.3:406ff.)

From about 4.20pm those with furthest to travel home started to head off. Others stayed around and sat in groups, talking, laughing, reminiscing, smoking, drinking. At around 5.50 we were asked very politely if we would leave as a theatre group had to set up in the area for an open-air performance of Goldsmith's *She Stoops to Conquer* that evening.

An old man at the flats came out to complain about the remains of the party moving to the communal garden. "*You can't come here with a dog!*" he objected. Brian grew quite irate. "*I'm fifty now! I can do what I like!*" he responded (1.3:141ff.)

Brian had planned that anyone still around later on in the evening, including myself as a researcher, should head off to a Sixties nightclub. As he explained to me the following day:

I felt I wanted to do something a little bit different ... I have always loved clubs ... nightclubs ... in the past, not that I have huge experience of the places, but ... er ... not having been to one for about ... four years or something, I just quite fancied just ... going out and having a bit of a dance... even... even though it'd be a... a standing-still dance... (1.3:529ff.)

The hot Brighton night at 11pm heaved with noisy, jostling crowds of mostly young people out on the piss. Scantily-dressed women in their late teens and twenties, in their gangs of three or four or twelve, eyed up the well-groomed packs of casual young men. The men eyed them back. Movement was all around, people coming, going, passing, stopping to look, being left behind and catching up. A sense of raucous, boozy enjoyment was mixed, I sensed, with a testosterone-filled threat of unpleasantness (though talking over this with Brian the following day, he said he had felt no danger in the air). A heavy-built bouncer admitted us into The Pavilion Tavern, a crowded bar with a shabby grandeur (that had obviously seen better days) in North Street. The disco was to take place upstairs, but would not start till 1pm. Two hours more of drinking first.

Toby Miller and Alec McHoul discuss popular culture as a sphere which idealises fun as the summit of all cultural pleasure. This fun is brought together by an exhilarating loss of self engendered by entertainment and its paradoxical everydayness; a combination of *wonderment* with *familiarity* (Miller and McHoul, 1998:3). Each of us sat knocking back pints, trying to follow what was being said by people sitting inches away, celebrating Brian's 50th birthday. This was fun and yet not fun. Brian reflected the following day:

...it was a ... lamentably chosen institution really ... it was an absolute dive that was ...er... really, seriously going downhill fast... (*laughs*) ...downstairs in the pub the music was extra loud heavy metal and ... people kind of sitting in sofas, drinking at ... voluble kind of speed ... just loud, angry music ...erm...it was atrocious... I think there was a palpable feeling of frustration and kind of ... what the fuck am I doing here... there were a lot of young people there ... er ... and ... and they all looked quite ... you know, sort of ... what would you say... quite trendy or well-to-do or whatever... there was just a general sense in the room of ... of people ... thinking what the hell am I doing here... there was not a single person who looked like they ... they enjoyed listening to heavy metal ... (1.3:529ff.)

In this situation Brian was no more or less disabled than anybody else, but was just one of the crowd. He was out with friends in the midst of strangers all of whom, like him, were looking for fun but seemingly not finding it. If fun is the summit of cultural pleasure it was elusive that evening. Yet it should have been here if it was going to be anywhere. While they had gone to a lot of effort to make themselves look good, people looked out of place, as if this might have been what they came for, but had decided since was not what they really wanted.

In Richard Schmitt's words, for the alienated self-esteem comes from:

Appearing acceptable, being liked, not being embarrassingly different... Because life just flows along, your person is a jumble of traits, activities, and thoughts that form no whole and make little sense... You must therefore look for recognition from others who are also just taking their life as it comes. You try to get along, to be respected, liked for not being different, for fitting in, for being familiar... (Schmitt, 2003:74).

Within the terms of popular culture this was about as good as it gets. Here was a Saturday night out in the centre of frantic Brighton, a bar with bouncers on the door to keep out undesirables (though I managed to get in). It does not get better than Saturday night out

drinking with your mates. Sunday would no doubt be spent nursing hangovers. Monday would mean a return to work, a requirement once again to conform to a different set of ‘institutional imperatives’ (Noble, 2003:93), and the start of another countdown of the days till next weekend.

I am reminded of Kevin, standing at his kitchen window in north Aberdeenshire, and I wonder whether he is really more separated from the passer-by cycling past his cottage than the young people sitting in the Pavilion Tavern are from those around them. Each plays a role expected within contemporary culture. If fun is considered the summit of cultural pleasure, then to suggest that access to fun is the greatest advantage the non-disabled have over disabled people suggests an advantage of dubious worth.

Charles: Eating Out

The door to the entrance is not particularly accessible

The waiter at the entrance holds the door open

He addresses me rather than Charles

Charles booked our table

There’s only three of them now

Says the waiter

To the waitress

Who is allotting us a table

(1.3:11ff.)

With Charles I went for a meal at The Stag and Rainbow, ‘a sort of Beefeater family pub’ (1.3:312) situated at a junction off a roundabout on a main road in West Derby in Liverpool. Charles and his family (his wife Caroline and their four year-old son David), come to eat here regularly, but on this occasion Caroline had to stay at home to look after David who had a tummy upset. Charles had contacted a friend, Erin, to join us for the meal:

...cos it wouldn’t have been much of an observation if it had just been the two of us... and also... you know... and also because I thought it would stimulate the conversation... (1.3:513ff.)

Erin was waiting in the chairs inside the entrance, reading a book, when Charles and I arrived. It was a dark wet night in late October. The waiter held the door open as I pushed Charles' wheelchair in. While Charles had booked our table, the waiter addressed me. Charles explained that we only needed a table for three now. The waiter turned to the waitress who was going to allot us a table. "There's only three of them now," he said.

As Charles said to me during our discussion about the event later on:

You see, disability discrimination works in subtle ways... and it's not always that easy to clearly identify whether something is or isn't discrimination... (1.3.548ff.)

Claire Tregaskis describes the way in which, while practicing inclusion, many non-disabled providers of services continue to hold negative and stereotyped views of their disabled customers (Tregaskis, 2004). It can be suggested that a demeaning judgement was being made in the waiter's addressing me rather than Charles and that an assumption was involved that I was Charles' 'carer' (in spite of the fact that he is a regular customer here). It is, however, in his use of the word *them* that it becomes more difficult to say whether or not discrimination took place. At best the waiter was simply rude, but it has to be questioned whether he would have used such dismissive language referring, for instance, to a family group of non-disabled people.

That this word should have jarred raises the issue of disabled people's heightened sensitivity to insult and objectification:

I think... it's actually quite hard sometimes to distinguish what is and isn't... you know... discriminatory behaviour... as you said it could be in a look... it could be in a tone of voice... or the emphasis of a word in a sentence... (1.3:562ff.)

Whether or not anything was meant by it, this was experienced by Charles as a reminder of difference that has often in the past, and almost certainly will be again in the future, been treated negatively.

The waitress escorted us to a table in an alcove, slightly set apart from the other diners. Again, it is hard to tell whether this was done with intention, perhaps out of consideration for other customers who may not have wanted to sit next to somebody with cerebral palsy while they ate. It was still early yet and The Stag and Rainbow was relatively empty. It filled up as the evening went on, and a family party made up of grandparents, parents and three children (out to celebrate Janice's birthday) was placed near us, as well as a young couple who hardly spoke to each other at the candle-lit table by the window, and a father with his two grown up

sons. The children at the next table keep turning round to look at Charles (1.3:249). We drank the Veneto merlot cabernet 2007. Charles and Erin mainly discussed management issues within various organisations of disabled people.

Discussing the evening afterwards, in terms of just going out for a meal, Charles reflected that it had been:

...I'd say pretty good overall... in terms of the pub... yeah, I mean there wasn't anything glaringly bad... maybe the bit at the start... when he spoke to you and not me... and said there's three of *them* now... (1.3:511ff.)

It is interesting to note Charles' comment about some of those who wait on diners at The Stag and Rainbow:

... bizarrely some of the staff who work at the nearby local authority day centre seem to be moonlighting there... so sometimes I'll go and they'll say "Oh yeah... you were our trainer..." I've not really had any specific issues there... but, you see, they saw me as a trainer... I don't know if that makes any difference or not... I suppose they can be patronising from time to time... yeah... what makes me laugh is that they're obviously not being paid much if they have to moonlight in the local Beefeater... (1.3:314ff.)

Charles cannot say whether or not being recognised as a professional disability equality trainer has any impact, lessening his chances of being objectified in this specific environment, although he does observe that the moonlighting day centre staff can still be patronising. What I consider revealing is that this occurs in a context in which normal power relations are reversed. Charles is the customer, the diner who is paying, who is recognised as an expert, while the day centre workers/waiting staff need to take two low-paid jobs and work day and night to make ends meet. Yet even here there is potential for misrecognition. While they might lead hard lives, at least they can count their blessings they are not disabled. That would be *real* tragedy.

Affirmation

Helen: Work

"They'd miss you if you left,"

"I don't want to leave,

Or if I do I want to be employed doing what I'm doing here.”

(1.3:146f.)

I spent an afternoon with Helen at her place of work, a mental health resource centre in Edinburgh where she volunteers as an information worker. While she agreed that her experience of mental health issues had ‘a little bit of influence’ on why she chose to volunteer with this particular service (1.3:217), the main thing for her, she stated, was

being good at the job.... providing a good service and getting good feedback and feeling like I've actually helped somebody... (1.3:219)

Helen's workplace offers an environment which, for her, is not disabling. Rather than being *in spite of* her mental health issues, she has discovered a line of work which she finds interesting and challenging *because of* her experience. Without this it is unlikely that she would have considered this sort of career, yet:

I've discovered that it's actually the information side of it is what appeals to me... (1.239ff.)

It is a role which suits her:

...it's somewhere I feel very comfortable... I feel very relaxed there... I feel very relaxed with all the people... so it's quite a nice sort of space... and I hope it is in general... cos a lot of the people coming in are quite stressed out so we try and make it quite calm... sort of a nice atmosphere... (1.401ff.)

During our conversation after work, Helen referred back to a discussion she had had with some other volunteers during the afternoon about their enjoyment of this work:

I think it's like we were discussing in the centre... and Alison was saying how it's great we're kicked out of the building at 5 o'clock... and I do, I think that's really important and I know in my own mind that I would not be willing to do a job that's going to give me all that expected overtime... which seems to be the standard now... because I know where it would put my health... and to me that is not worth it... (1.3:513ff.)

Helen recognises her impairment and the needs arising from her impairment. She does not try to hide or deny these, but recognises them as part of what makes her who she is. She also

recognises the disabling requirements that exist in many workplaces and says she will not put herself into work situations which she knows would damage her health. Helen talks about a comment made by one of her colleagues:

...but I think it's like she was saying, if you want to do something different from the normal expectation it's as if you're doing something really controversial... why is it controversial to want to do something that's better for yourself... and I think it's almost that I've had to become... well, if not exactly militant then very firm in my view of what works for me... and to be willing to stick to that because when you keep coming up against people who say well, are you sure... I go well, yeah, I am sure... just because it's not how you would do it doesn't make it wrong... I think that's the thing that, like, if people showed appreciation of the fact that people just do things in different ways it would be very helpful... (1.521ff.)

At the same time as Helen affirms her rights to recognise her own needs as somebody with an emotional impairment, she rejects the disabled role. She rejects an identification of herself as somebody unwell or inferior and she rejects the pressure to aspire to normality. But she also identifies the necessity to remain strong in this perspective in the face of disabling judgements which will always question her right to regard her situation in this way. Helen ends up by asserting and affirming the right to do things differently.

I sometimes feel that other people feel that maybe I should... and that maybe I should keep my mouth shut... and not try to mark myself out... but to me it's not that I'm trying to mark myself out, it's that I'm trying to make it more normal... so that it's more acceptable so that it is easier for everybody... (1.3:480ff.)

Her experience is that she will be generally expected to keep quiet about her difference. As somebody with a hidden impairment, she is encouraged to try to pass as non-disabled and avoid the stigma attached to mental health issues. Her attitude is dismissed as attention-seeking. Yet for Helen, this is a matter of trying to demystify issues around mental health issues, of trying to establish that this is a fairly ordinary part of human experience.

Jennie: Work

Jennie took me into her work area, a small, high ceilinged cluttered room off the main living room in her shared Glasgow flat. Most of the space was taken up by an old office desk. On the desk, among a mass of papers, a p.c., and a dictaphone for interviews, there was a half-finished bottle of Irn Bru, a bottle of water and a bag of ginger. The walls were lined with

crammed bookcases and decorated with old maps of the world. A micromark heater was switched on and giving warmth. I was there to observe Jennie making a start to her working day:

I'll normally get up... I'll go through... I'll take my pills and my blood pressure... and then usually just take a cereal bar straight into the study... and work there right away... the time of this varies depending on other aspects of my schedule 'cos sometimes I'll end up working here till after midnight... so I won't necessarily be back at eight the next morning... also, of course, often I'm sick in the mornings so that affects me to some extent... but usually I'm well enough to go to my desk while I wouldn't be well enough to go to a job somewhere else... (1.3:113ff.)

It is from this study that Jennie runs her own business, a media company established two and a half years ago:

... well, at least we've been live for that long... we reach about 200,000 people a month... that's been climbing month by month since our inception... and we cover all aspects of the film industry... we're attempting to make independent film more visible... (1.3:146ff.)

When talking about how her support needs are met, Jennie discussed the close relationships she has with her flatmate John and her two partners, Hugh and Alasdair. Hugh also lives in the flat while Alasdair lives in a flat across the road. These relationships involve a sharing of skills and abilities in order to support each other's requirements, in terms of work, studying, cooking, getting about. For example, Jennie proofreads for Hugh, who is dyslexic (1.1:348). Alasdair will cook hot meals for Jennie as she cannot herself carry out the practical tasks involved in cooking, such as lifting pans (1.3:299):

...we basically manage things as a group of us... erm... Hugh does most of the housework here in the house and I work and bring in money, basically... erm... and Hugh studies as well... Alasdair's a photographer, so he's on flexible hours most of the time... he does a lot of practical stuff for me... but Alasdair couldn't cook at all when I first got together with him five years ago... so I've basically taught him to cook in exchange for him doing the work... and that works out... and Hugh makes me food from time to time as well... and Alasdair helps me to get about to places... he's the person I feel safest with, pushing my wheelchair when I have to be in that... (1.3:286ff.)

Tom Shakespeare has suggested that disabled people suffer when, in order to have their support needs met, they have to rely on unresponsive services or demeaning charity which renders them marginalised and dependent:

Yet empowered disabled people will achieve a better quality of life in a community in which each recognises their responsibility to the other, rather than a world made up of competing and selfish individuals seeking to maximise their own advantage (Shakespeare, 2000 :82).

The model of caring solidarity demonstrated by Jennie, her flatmate and her partners ensures that while impairment effects are acknowledged and addressed, this is done in a way that does not involve disabling roles being assigned. As Jennie adds:

I think I depend on them for things and they depend on me for things... it's the same in any relationship... and the sooner you acknowledge that in a relationship and stop worrying about who owes who what, the easier it is just to get on and be human beings... (1.3:348ff)

This is perhaps the acknowledgement that Markell speaks about. Each is open to her or his own vulnerability and accepts that this will be met by others. At the same time, each is prepared to give of one's self in order to meet others' needs. In case this all sounds too idealistic, Jennie's last statement to me should be considered:

I won't pretend there are never arguments about any of it, but that's not a big deal... I mean, you take these things in your stride... (1.366ff.)

Lola: UK Chatterbox

There we go, I'm Mistress Keen...

Sound of typing.

(1.3:419ff.)

Lola had been unwell for some time when I visited her in London.

I haven't been terribly well and it's... it's the grey area of impairment that we don't yet feel ... widely comfortable discussing, I think ... some of us do and some of us, I think, are able to do that more than others because you ...it's starting to change, but ... just the fact that ... erm ... even in the most perfect Utopian, social model

society, er ... like, life... I'm sure you will relate to this... that life *anyway* is challenging... we're not gonna eliminate that... (1.3:6ff.)

Lola gives assent to Swain and French's view that, even in a social world where disabling physical barriers had been removed, it would still be possible that impairment could be regarded as tragic (Swain and French, 2000). Living with impairment can be nasty and unpleasant and Lola's statement that she experiences grinding, unrelenting pain (1.3:52) demands that this is recognised. However, Lola is emphatic that even with her pain she would still rather be herself than not:

I'd rather be me than not be the whole mix you know... positive, negative, flawed, happy, sad mixture... that I am... you know that makes me *me* ... erm ... and you know, you can play the sort of games with yourself, thinking ... well, if you had that or you didn't have that would it still make you who you were... and I don't believe I would be the same person... (1.3:171ff.)

The need for an affirmative model is suggested again by Lola's observation that many disabled people feel uncomfortable talking about impairment for fear they will be understood as validating assumptions that disability is really, after all, about something *wrong* with people. She expresses a hope that it will become possible for disabled people to talk openly about the reality of their lives without the need for impairment to be seen as a mark of misfortune:

...and again, this can be quite difficult to talk to some people about 'cos it veers into some tragedy model or bravery model or whatever, in that I do think that developing strategies for pain or how you manage them can be an empowering experience... I don't really give a fuck what anybody else makes of that... but I think it's valuable and I hope one day... we... us crips can talk about that a little more without worrying that we're falling into the bravery model, 'cos obviously I don't think it is about bravery ... (1.184ff.)

In Lola's following remark the idea is confirmed that disability is not an individual characteristic, but a relationship or a role. While she identifies as somebody disabled by physical and social barriers, there are times when she is so caught up in the business of existence that the experience of disability, even of impairment, is forgotten:

...what's interesting for me is I probably *do* live my life, erm ... quite consciously, as a disabled person... so... I know that's quite different to ... as you say, we don't go

around thinking *am I compensating... am I suffering...* sometimes I forget I'm a disabled person... depending on what I'm doing...and actually going for hours without being conscious of my wheelchair or my impairment and you know ... even the pain, actually... to some extent.... and I'm a writer or a friend or a lover or a ... an aunty or whatever and I go those roles as well... (1.3:232ff.)

Given appropriate environments and contexts Lola's point is that, far from constantly overshadowing everything she thinks and does, disability and impairment is often the last thing on her mind.

I want to characterise Lola's visit to the *UK Chatterbox* website in terms of Certeau's tactics of resistance. In logging in she is doing nothing except having a laugh, enjoying a bit of mischief, being slightly naughty, taking the piss. While she does sometimes play mind games with some of the male punters around body image and descriptions, this has little to do with disability other than to subvert its constrictions. She sticks two fingers up at assumptions. *L* here is Lola and *C* is Colin.

L; *Cheeky Sam* who said *hi ... I'll say 21...* see, I would wanna go *aren't you in bed yet...* or whatever... I can be as outrageous as I want... where's that... *as long as sexy... all kind and kind and good...*

C: *Like younger guys...* this guy's asking ...

L: (*typing and laughing*) ...*How do you define sexy...* cos ... you know, again we're on ... there's so many ... *Blue-Eyed Taffy...* how old's he... thirty-five... (*types*)

C: *What are you after... hee hee...*

L: 'Cos some of those... if you just say what you're after, it can sound a bit aggressive... that's not a bad response...

C: No... Mistress Keen has asked *shouldn't you be in bed yet...* to Man in his 20's and Cheeky Sam has replied *only if you mean yours...*

L: Erm...

C: Lola's now writing *I thought Mummy might have tucked you in by now... lol...*

More typing.

C: *Or do you need a Mummy to do it for you... with extras...*

(1.3:503ff.)

While the transcript of this observation is a little hard to follow – it is an attempt to capture in writing an audio recording of several online conversations happening simultaneously – its meaning is, I think, clear. Shortly after 5pm Lola went online and entered the UK Chatterbox chat room designated for London punters in their 40s, introducing herself as Mistress Keen. Within minutes she had dozens of men (or, at least, people identifying themselves as men) wanting to engage her in flirtatious, if not downright seedy, ‘chat’. While there may be wider questions about issues of vulnerability among disabled chat room users, Lola is an experienced woman who has divorced two husbands, published a volume of erotic stories, and performed burlesque at the Edinburgh Fringe. She is neither shy nor desperate. Her visit to this chat room is made purely for purposes of self-gratification and a vaguely dirty feeling of amusement. While, perhaps, if Lola created an alter-ego online identity for herself that was slender, beautiful and non-disabled it might be argued that this activity involves some sort of attempt to compensate for repressed sexual urges, her sense of humour inclines her rather to make statements like:

*I am twenty stone... erm ... actually I could say... I'm twenty stone, five eleven...
I'm a bit taller than him... with a huge minge...* (1.3:591f.)

The only time disability is mentioned during Lola’s visit to *UK Chatterbox*, it is with a dark humour:

*I quite like that... (types) sorry, but you know a girl has to keep men waiting...
where is the one I said ... is that... I fell getting off the train... (laughs) ...are you a
cripple...*

Both laugh.

L: Shall I ... shall I ask him, *what are you some kind of cripple...* I don’t know if I can be quite that... mean. *(types) ...let’s do a flat statement... not the ugly ones... you know a girl has to keep you all wanting... how do I tell that... you all tell me you’re hot and handsome...* (1.3:569ff.)

At length, however, after about twenty minutes, the pleasure begins to wane. Lola acknowledges her amazement at how easy it is to play men (1.3:577):

L: Okay... God, who's this one... *May You Live Forever*... thirty-one... where's Mr Exec... right, yes especially... I told him I'm ready for anything... especially for... shall I say *rampant fucking*...

Both laugh.

L: You can see how stupid this is, then...

The amusement palls. Lola recognises that, while this might have been temporarily distracting, it is a frivolous use of time:

L: But, you know, I don't wanna waste my... kind of skills, almost ... on these banal shits for too long ... (1.3:666ff.)

While Lola was Mistress Keen she was a woman amusing herself at the stupidity and gullibility of the sort of men who visit internet chat rooms. This does not suggest that she was intent on forgetting her impairment and the pain caused by her impairment, but that sometimes – a lot of the time – impairment is not what is foremost in her thoughts. It does not suggest that she deliberately ignored her impairment and the pain caused by her impairment, but that sometimes – a lot of the time – impairment does not seem particularly worth thinking about. Sometimes disabled people just enjoy themselves in messing about, not because they are disabled but because they want to and can.

Roshni: Work

Kailyn: I am *an ill person* wherever I go

(1.3:331)

In *Further Towards an Affirmation Model* I argued that when disability is understood as oppression it is to be rejected rather than affirmed (Cameron, 2008:23). I was taking issue with Swain and French's suggestion that there are benefits of lifestyle in being disabled (Swain and French, 2000:569). I argued there is a difference between affirming self and the implication that, because it is possible to deal with negative experiences positively, it is therefore sometimes good to have had these imposed.

I did not mean, however, that given the reality of the experience of disability as oppression, there are not parts of life that can be enjoyed in the context of relating to that oppression. The

sense of solidarity and purpose that can be gained from identifying with other disabled people in challenging disabling barriers is an example of this.

I met Roshni in Glasgow on a Saturday morning in February 2009 to observe her facilitating a meeting of a group of five young disabled Asian Glaswegian women. She had been working as development worker with this group for about a year to raise disability consciousness, and described the experience as something which motivated and excited her:

...this particular project I thoroughly enjoy working on and I get a lot from it... especially, you know, you wake up on a Saturday and it's the last thing you want to do... come to work... but when I come to these meetings I feel that I get so much from them in the sense that I feel that I'm able to give a lot of myself... and hopefully I'm able to gain a lot as well from everybody else's experiences... and it's in a different way to the way in which I interact in the other work that I do... because I find that I'm doing it because I need the money... because I have to pay my mortgage... because I have to do boring things like that... whereas this piece of work, yeah, I'm getting paid for it but it's a lot more... it draws on my own passion a lot more... (1.3:18ff.)

That Roshni found pleasure in this work did not signify that it was necessarily easy or pleasant. In the meeting she and the women talked about the ways in which this group had provided the first ever opportunity for some to talk about experiences of almost total isolation, of humiliation, of voicelessness, of absence of control over life events:

„and in the process of doing that you uncover lots of instances of abuse in some cases... emotional abuse or physical and sexual abuse... (1.3:61f.)

Roshni told me that there had been some women who had started to come to meetings but had stopped because they had been:

simply not been able to handle it... because it's just such a leap in logic for them... in terms of the kind of setting that they have come from... and that they've experienced all their life... (1.3:110ff.)

The intense negativity experienced by these young women meant a very long journey in moving towards a more positive self-image. Among the issues identified by Roshni as causing most difficulty in terms of trying to progress was the lack of vocabulary with which to positively represent and talk about issues around impairment and disability:

...on top of all that you don't have language to express these concepts... you can say that we don't have the language in English either, and that the disability movement has had to create a lot of that and carve out new contextual meanings for words... but the problem you have with languages like Urdu and Punjabi is all of the language we have is in the negative... every single thing... even the words that are used to define or to describe certain impairments are all based on what you can't do... so whereas here we would talk about somebody as being visually impaired a literal translation of that into Urdu and Punjabi would be *can't see...* or *their eyes don't function...* or *don't work...* (1.3:86ff.)

Surinder, one of the women in the group, said that this difficulty is compounded by the cultural silence about or avoidance of discussion of disability: 'Because disabled people are hidden away these words are just not used' (1.3:330) When even negative descriptions of impairment are rarely heard because the subject is felt to be shameful, the activity of generating an alternative discourse becomes an impossible task.

So often do they hear that they are good-for-nothing, know nothing and are incapable of learning anything – that they are sick, lazy and unproductive – that in the end they become convinced of their own unfitness (Friere, 1974:45).

Friere's words are given a chilling echo in Kailyn's:

You hear so often you're rubbish that you end up believing it... (1.3:331)

While this work involves addressing some extremely sensitive issues, Roshni was clear that it was not a heavy experience all the time. She talked about the way in which the women involved frequently used it as a safe space within which to sound off (1.3:248):

everyone's up and out there... and a bit loud and a bit silly... and not very p.c... but learning a lot... and learning in a very different way... (1.3:113)

It is not that the experience of being disabled is to be affirmed, but that an affirmative stance taken in relation to the impaired self in the face of oppression can lead to immense satisfaction. Towards the end of our discussion, Roshni talked about why she values the opportunity of coming together with other disabled people. While people may have had very different life experiences, her view is that:

...because all of you have that one shared experience of that discrimination, as it were... so you are able to connect with it and share it... but at the same time, by

sharing it you gain so much strength by knowing that you have that... if you like, sisterhood or brotherhood of people who are there to support you and who have shared values... and you know that no matter how crap it can get, you know that collectively you are able to make an impact... on the environment around you... and so I think sometimes that sharing it and being able to let go of it can actually be really powerful in terms of strengthening you... (1.3:252ff.)

Ben: Birmingham New Street

I met Ben outside WH Smith's at Birmingham New Street railway station. We had agreed to reconstruct his twice-weekly passage between platforms on his journey between Coventry and the university he attends. As somebody with autism Ben describes this as an unpleasant but necessary experience which he tries to get over as quickly as possible (1.3:390ff.) It involves going up one escalator and hurrying to another down to platforms 2 and 3, unless there has been an alteration. It is an underground station which creates a sensation of enclosure filled with noise: people all around talking, trains revving, revving becoming throbbing, clattering running footsteps, trundling wheels of suitcases, piercing whistles, incessant announcements about trains, platforms, platform changes, delays, departures, informing people that smoking is not permitted anywhere in this station. On this day as well Pudsey Bear rattled his collecting tin for *Children in Need*. Ben says he regards it as an endurance event to get through:

the noise is

the biggest

thing

it's inside

of me

it's taking

up all my

processing

capacity

if I pick up

an announcement

about my train

that will be

quite by

accident

(1.3:58ff.)

Ben describes his feelings of intense anxiety among the crowds (1.3:150):

I go in the

same direction

as everyone else

I can't do

anything else

I feel

vertiginous

I feel

off-balance

I like

my own

space

but in

crowds

I don't

have any

space

(1.3:140ff.)

It was only during this observation, because he was reflecting on his journey in a way he would not ordinarily have done, than Ben became clearly aware of conscious patterns he has formed for himself in his frequent re-treading of these steps. He relies on the repetition each time he repeats this passage of certain movements, decisions, thoughts, signals, sights which reassure him that he is nearing his destination:

I've got

systematised

I have

developed

a set of

internal

rules that

effect the

decisions

I make

I am

imposing

a sort of

structure

on the

situation

I can't

just do it

at random

I would not

normally think

of them

as rules

but now

I'm thinking

about them

it becomes

apparent

(1.3:249ff.)

By imposing structure every time he passes through New Street station, Ben is able to manage this journey. It is when things happen unusually that he becomes anxious. For example, he becomes irritated when people will not stay put on the escalator (1.3:196). He stated that 'if this were a station I wasn't familiar with it would be overwhelming' (1.3:104).

The recognition of his need to impose structures, to do things his way even if this is not the way others would do them, is not something that worries Ben:

My attitude is you do what you do... you just do... it's Zen, if you like... because you can't do otherwise... it's a way... just one way of... everyone has a different way... the way I do things is a way which has developed between the interaction of me, the physical environment and the social environment... and we're all a part of that mixture... and there isn't any sort of moral difference in that... in terms of a brave struggle and all that nonsense... no, I don't subscribe to that... (1.3:581ff.)

He rejects a view which places a requirement on individuals to conform to ideas that there are 'right' and 'wrong' ways of doing things, affirming instead the rights of people to go about things in ways that suit their own needs. Identifying the oppression inherent in trying to enforce a standardisation of behaviours, he stakes a claim for the equal valuation of difference:

Well... the point is the way I do things is normal for me... the way other people do things is normal for them... there isn't this hierarchically-imposed normality which everyone should aspire to and if they don't live up to that then they are... in some way either to be compensated for or not bothered with... disposed of... swept away under the carpet... (1.3:591ff.)

After the tension involved in crossing New Street station, it is a relief to Ben to climb aboard the Coventry train:

I feel happier
once I'm on
the train
once it
sets off
I plug in
my phones and
switch on
my mp3 player
new agey
sort of
stuff
chill out
ambient
I'll try and
switch off
(1.3:395ff.)

We get a different picture of Ben here. From the tense, stressed-out man with autism freaked out by disabling distractions as he hurries from one platform to the other – managing to keep a hold on things only with considerable effort – we now regard somebody at home with himself and in his own body, heading for Coventry, tuned in to tranquillity.

Conclusion

Max Van Manen has stated that lived experience has a temporal structure which can never be grasped in its immediate manifestation but only reflectively as past presence:

Our appropriation of lived experience is always of something that can never be grasped in its full richness and depth since lived experience implicates the totality of life (Van Manen, 1990:36).

Of necessity the snapshots I have discussed in this chapter have been partial representations of the events I was present at as an observer. I have relied upon notes of statements, objects, occurrences, fleeting images jotted down at the time as they appeared, and on transcriptions of reflective discussions anticipating and evaluating these events. I am aware of both the limited nature of the descriptions I have given and of my analyses of these as accounts of the particular moments I have focussed upon.

While I have discussed examples of the imposition of the disabled role, alienation and affirmation within contexts of separate observations, within each observation it would have been possible to discuss moments when each of these themes appeared as a possible focus for consideration.

For example, I constructed my discussion of going with Charles for a meal to The Stag and Rainbow to make a point about the alienation of the non-disabled waitresses there. This necessarily meant omitting many other details occurring and things we talked about during the evening. It would have been equally possible to have highlighted other moments in order to consider the imposition of the disabled role or examples of Charles' affirmation of self. While I constructed my discussion of my observation with Mary as a reflection upon the imposition of the disabled role, I could have highlighted the alienation of other characters appearing, or moments of affirmation; and so on.

In describing writing about lived experience, Van Manen talks about a passage by Jean Paul Sartre entitled 'The Look', in which Sartre attempts to convey a sense not just of what it is like to spy on someone but also what it is like to be seen looking at someone in this manner:

Sartre describes how the act of looking at someone through a keyhole (motivated by jealousy, curiosity, or vice) is experienced in “a pure mode of losing myself in the world, of causing myself to be drunk in by things as ink is in a blotter.” However, when all of a sudden I hear footsteps and realise that someone is looking at me, an essential change occurs in my mode of awareness. Where moments before my mode of being was governed by unreflective consciousness, now “I *see* myself because somebody sees me. I experience myself as an object for the other” (Van Manen, 1990:24).

I am reminded of a statement made by Charles which, I think, not only captures and expresses Sartre’s idea but also highlights the way in which each of my three themes in this chapter (the disabled role, alienation, affirmation) can be regarded as being experienced, if not simultaneously, then almost simultaneously.

...when I was talking in the pub with Erin and yourself tonight... with every sentence I wasn’t thinking oh, I’m going to say this sentence with a speech impairment... blah blah blah... now I’m going to say this with a speech impairment... blah blah blah... I’m going to move back, but I’m moving back in my wheelchair... you know... you don’t think... but... when you catch somebody looking at you... and looking at the effects of your impairment... concentrating on your impairment... then you’re suddenly aware... that you’re speaking differently... (1.6:617ff.)

While Charles had been talking dismissively with Erin and I about the Leonard Cheshire *Creature Comforts* advertising campaign, a waiter had come up behind where he was sitting in his wheelchair to enquire if we wanted any more drinks (1.3:221ff.) While his consciousness was focussed upon the presence of Erin and I, Charles had been holding forth with eloquence and humour, pausing occasionally to sip his veneto merlot cabernet 2007 through a straw. In our company Charles was able to be his usual laid back entertaining self. This relates to affirmation. When he became aware of the gaze of the waiter standing behind him, Charles’ mode of awareness changed: he became an object for the other, and aware of himself as an object of scrutiny, fascination and perplexity. In other words he became aware of himself as a disabled person. This relates to the imposition of the disabled role. The waiter – a young man – had hovered behind Charles for longer than is usually considered acceptable in terms of restaurant etiquette. Presumably waiting for what he considered an appropriate break in the conversation to make his intervention, relying upon cues and tones in what was being said, he had been thrown by Charles’ speech impairment. He had cast a number of appealing glances in my direction before Charles picked up on my body language

responding to these appeals, and made his own shift in awareness modes. It is in the unpreparedness of the waiter to encounter difference, and in his uncertainty about how to respond to difference, that I would suggest the theme of alienation arises. An expectation of sameness and predictability suggests comfort with only a restricted notion of humanity.

Every self-affirming act performed by a disabled person that validates their own subject position as an impaired person involves an act of transgression. Against a barrage of expectations about what a disabled person should be 'like', viewed in terms of a narrow range of stereotypes, to assert the right to be valued as an impaired person involves a challenge to dominant perceptions. Affirming one's right to participate in ordinary life does not involve emphasising one part of one's self/identity/physicality above others; but neither does it involve seeking to distract attention from impairment.

Acts of transgression can be made in the most mundane circumstances and by anyone. Going into a cafe for a cup of coffee, making a point of asking for Mozart cds, entering a travel agents to book a holiday, figuring out how to get to platforms 2 or 3: each of these – whether consciously or not - can involve making a demand to be respected and included that goes against the grain. Each can involve an unapologetic assertion of the right to be acknowledged and included as an equal. Perhaps this is neither necessary nor inevitable – it would be equally possible for somebody to be reticent or fearful or embarrassed about doing each of these things – but the possibility is there. It is about asserting the right to be part of life rather than waiting for permission to be given.

In closing this chapter I want to return to one of my original research questions: is the social model of disability adequate as an explanatory tool for the description and analysis of psycho-emotional experience of living with impairment in a disabling society?

During my last visit to Liverpool, Charles and his wife Caroline very kindly offered to put me up for the night. After we returned from The Stag and Rainbow, and over a bottle of whisky he produced, Charles and I sat at his dining room table and talked about what had happened during the evening. Later we were joined by Caroline and the conversation broadened to cover a wider range of the couple's experiences of disability discrimination within everyday life.

An issue both talked about was the experience of prejudice from other parents of children at their son David's nursery. Caroline described the hurt they felt when, after all the children in David's nursery class had received invitations, nobody had turned up to his third birthday party. On his fourth birthday they had again given out invitations, and two parents had

brought their children along. Neither parent said a word to either Charles or Caroline during the whole party except to say “Bye” at the end (1.3:843ff.)

I asked whether, on occasions like this where there is the potential to experience great rejection and sadness, at the subjective level and at the moment when that sense of insult is felt, there is strength to be drawn from the social model. Caroline replied by saying no (1.3:971). For her the social model is something she might apply later in order to rationalise the experience, but does not speak immediately to her emotional self. I wondered if:

at the level... at the really personal, emotional level you're talking about, Caroline, or maybe where you feel that pain, or that tiredness, that fatigue, that extra stress... whether you feel that that is something you feel the social model is fully able to address... (1.3:1006ff.)

Caroline's reply was that:

Not for me as an individual it isn't, no... it isn't... cos the thing is as a disabled person you can be political... but most of us... certainly... I'm speaking for myself now... there are some days when I just want to crawl under a stone and I don't want to... I don't want to associate myself with being a disabled person... cos I'm sick of the fight and I'm sick of the battles and... because, you know, sometimes things do get really personal... largely other people's attitudes... but it still has a personal effect on your life and can sometimes make you feel shit... (1.3:1012ff.)

Even Charles, who has expressed doubt about whether an affirmative model is needed when we have the social model, conceded that:

It's hard to walk through life and constantly experience shit... constantly experience negative attitudes... and think... ah... that's a social barrier... (*laughs...*) (1.3:1024ff.)

I do not suggest that, as a theoretical model, the affirmative model is able to do the impossible and become incorporated as part of disabled people's emotional experience as experience happens. As Van Manen states, there is a difference between being-in-the-world as non-thematic consciousness and the processes by which we give meaning to that being:

Life experiences gather hermeneutic significance as we (reflectively) gather them by giving memory to them. Through meditations, conversations, daydreams,

inspirations and other interpretive acts we assign meaning to the phenomena of life (Van Manen, 1990:37).

While I would suggest that the social model is an abstraction that can be used in an intellectual way to explain the processes by which disability is imposed, my hope is that the ideas expressed within my proposed affirmative model definitions might speak to and shade our meditations, conversations, daydreams, inspirations and other acts of interpretation.

Conclusion

I conclude by re-visiting my five substantive questions and asking whether these have been answered within my analysis. While I do not claim to have attempted to address these directly, I can state that they have been hovering in the background, shaping my lines of exploration and enquiry. I address each question in turn.

Is the social model of disability adequate as an explanatory tool for the description and analysis of the everyday experience of living with impairment in a disabling society?

The social model was initially developed as a practical tool in order to understand the externally imposed restrictions which limit the full participation of people with impairments in society. Where it does relate to impairment and to medical or therapeutic treatment, the social model identifies the suffering caused within disabled lifestyles as due primarily to the poor organisation of services (Oliver, 2004:22). While many disabled people (myself included) have found the social model liberating in terms of the light it has thrown upon the circumstances of our lives, it is to expect too much of it to account for or provide all the answers to every conflict experienced by every disabled person in every instance. In a commodity culture alienation is endemic and is felt by more than just disabled people. There are other causes of oppression than disabling barriers.

We recall Brian's characterisation of disability as 'a wide vista of experience...' (1.1:140) impacting on both objective and subjective reality. To suggest that the social model is not the right tool to use in attempting to understand the deep emotional hurts that disability involves is not to criticise it, as this is something it was not fashioned for. I have characterised the social model as enabling an understanding of the disabled self within the broad historical sweep, and would suggest that in relation to the self it is not required to do more.

In what ways do media representations of disability impact on the identities of disabled people?

I have suggested that media representations of disability as personal tragedy function ideologically to harness the willing participation of disabled and non-disabled people in the daily reproduction of disabling social relations. The endless reiteration of the view that impairment is undesirable difference reinforces an economics of conformity, a fear and avoidance of being regarded as different, and an unending pressure to appear as normal.

In Sarah's words 'it's only ever either one way or the other... there's sort of the timid... or there's the angry...' (1.3:341). When media present only two options as ways of being – passive victim or determined struggler - the disabled role is imposed in such a way that it is made difficult for people with impairments to enjoy themselves as who they are.

How useful a concept is 'disability identity' as a tool to people with impairments in making sense of their own experience?

I have argued that disability identity enables people with impairments to address the circumstances of their lives in ways which resist the sense of personal inadequacy that mainstream culture works to impose. Taking on a disabled identity involves a revolution of personal perspectives, so that instead of trying to shoulder the weight of disabling structural relations, as if the resolution of these is to be found within the self, these can be addressed collectively.

And I suppose wished that I wasn't... but then, looking back, you're wishing not to be... the way that you're being treated... that's what's at the heart of it... (1.1:262ff.)

The disabled role imposed by mainstream society suggests two ways of responding to the experience of impairment. Both involve a rejection of self. Charles' words draw us into a personal recollection of time he spent uselessly punishing himself, regretting his physical embodiment. The other response suggested and applauded by the mainstream involves attempting to transcend impairment. Both types of response involve self-oppression and neither brings about social change.

Taking on a disabled identity – in the political sense I have described – involves recognising one's own situation in a disabling society. It is in taking on this identity that people with impairments place themselves in a changed relationship to the social and cultural processes of disablement.

Is the affirmative model an adequate explanatory tool for analysis of the cultural construction of disability?

I am what I am whether or not I have a label and... erm... it's basically something that people impose upon me in different situations in different ways... erm... in my

dealings with the world is when I feel it... it is not when I go to bed at night...
(1.1.366)

Ben's statement expresses my meaning in describing disability as a role. My intention is that the affirmative model will be used by disabled people to make sense of this role as it is imposed within the minutiae of everyday life. If, as Neil Thompson (1998) suggests, our understanding of our own personal situations is indelibly shaped by cultural arrangements reflecting the structural base of society, there is a need for tools which equip us to engage with cultural as well as structural oppression. Having subjected the affirmative model to sustained critical analysis, I suggest it can be described as adequate for this purpose.

Is the affirmative model an adequate explanatory tool to account for both recognition and redistribution issues in relation to the experiences of disabled people?

The affirmative model definitions proposed here allow us to regard impairment as a valid human characteristic among other human characteristics. This does not involve a denial of the sometimes painful aspects of impairment, but neither does it regard these as marks of inferiority. The affirmative model provides the basis for a self-respectful stance to be taken in the face of cultural assumptions of personal tragedy. It contextualises the experience of impairment within current discourse on diversity and establishes the rights of people with impairments to be recognised and valued as who they are.

While my definition of impairment addresses recognition issues, my definition of disability as role addresses issues of redistribution. I have described the disabled role as an alienated role among other alienated roles in a culture which actively produces and requires alienated human beings. The disabled role is imposed on people with impairments to remind non-disabled and disabled people alike of the value of conformity. Pre-occupation with conformity as individuals diverts collective focus from wider structural issues of inequality. As a framework which throws new light on processes which legitimise inequality in contemporary society, the affirmative model can be used as a tool to address the unequal life opportunities experienced by disabled people.

While I conclude that the affirmative model is an adequate explanatory tool to account for both recognition and redistribution issues in relation to the experiences of disabled people, I suggest also that it is a model which opens up debate in new terms. In requiring

acknowledgement of disability as an imposed role, a challenge is thrown out to those involved in imposing that role to reflect upon what meaning for themselves is constructed through their own actions. A requirement is placed on non-disabled people to acknowledge their own temporality and the structures which support the myth of their invulnerability.

Final words

Other writers in Disability Studies have made similar points to mine. Bill Hughes (2007), for example, has discussed the invalidating ways in which non-disabled people relate to disabled people. Sally French has described the disabled role as involving expectations and assumptions that disabled people will strive to be physically independent; that they will take responsibility for the feelings of non-disabled people; about normality; about acceptance and adjustment (French, 1994) These arguments, however, have been made in the context of a continuing discussion and debate around the social model. Even among critics who see it as being in need of adjustment, there is a settled will that the social model can provide the answers to the problems of disability.

My position is that the social model does not need adjustment as it is well able to do what it was intended for. I accept, however, that as a theoretical framework it has limitations. It should not be expected to do what it was not intended for. There is room in the field for other tools developed by disabled people that are designed to make sense of disability. My original contribution to knowledge has involved the clarification of the affirmative model, an idea originally suggested by John Swain and Sally French in 2000. I have sought to clarify this term so it can be made useful for disabled people rather than remain a good but under-developed idea. I have grounded my version of the affirmative model in the statements and insights of sixteen disabled people I have talked with during my research. I have, furthermore, scrutinised the affirmative model in the light of participants' discussion of media representations of disability as narratives to draw on in constructing identities, and in the light of their everyday experiences. Having subjected the affirmative model to such scrutiny, I feel able to confirm its validity. I am, of course, aware that my version of the affirmative model may depart in some details from Swain and French's original intentions but I am confident that its substance is in tune with their meaning.

I accept, as well, that my argument is built on my analysis of conversations with sixteen particular disabled individuals at a particular point in time. I do not suggest that my version

of the affirmative model will hold good for ever and in all situations, or that it should be necessary for it to do so. If an affirmative view gains ground so that increasingly impairment becomes expected and respected on its own terms as a characteristic of human difference in a diverse society, so that people with impairments are increasingly able to participate as equals in ordinary community life without having to encounter stigma, intolerance and the experience of being patronised, there will be no need for an affirmative model. In the meantime, however, I propose it as another useful tool.

Stanford Lyman and Marvin Scott suggest that the fundamental question of sociology is the Hobbesian question: How is society possible? (Lyman and Scott, 1970:111) I believe that my thesis has not only answered my own research question and my substantive questions, but provides new insight into this larger question. Society has been made possible by ascribing a negative role – the disabled role – to those whose bodily configurations pose a challenge to requirements of conformity. Nobody likes being disabled, and the challenge is to find new ways of making society possible.

Ideas for further research

An oral history of the disability arts movement

An existing awareness increased during my research, for example in conversation with Sarah, that among many disabled people there is very little knowledge of the history of the disabled people's movement and even less of the disability arts movement. Strong disability identity can only be based within knowledge of shared experience. While a history of the movement as a whole has already been produced by Jane Campbell and Mike Oliver (1996), and a chronology of events within the disability arts movement has been produced by Allan Sutherland (2009), there is a gap that needs to be filled of the recollections of those who were involved in shaping the disability arts movement at its beginning. This is an issue that gains importance the further we move from the 1980s as many of the disabled people involved at this time have since died.

An exploration of the use of the affirmative model in reinvigorating the disability arts movement

During my second discussion with Brian, who is closely involved with the disability arts movement, I detected a sense that this is a movement in decline for a number of reasons. Of central importance here has been the withdrawal since 2008 of funding by the Arts Council

of England from organisations such as Disability Arts in London and the National Disability Arts Forum, leading to the closure of these bodies, and the imminent closure of the Scottish Arts Council's Equality Unit. Another major factor has been the distancing of themselves by artists who have gained some success within the disability arts movement from their community arts origins. It would be of value to conduct exploratory research asking whether the affirmative model could be used to reinvigorate the movement from which it emerged as an idea.

The affirmative model and narrative practice

Useful research could be carried out to explore ways in which the affirmative model could be used in popular education aiming to engage in critical conversations with disabled people as a process of revealing that established narratives do not describe the only possible realities. To this end I have in mind the development and trial of a series of illustrated stories and vignettes which could be used as the basis either for one-to-one or group discussions and reflection.

Developing the sociology of the absurd

Further exploration of the everyday life experience of people with impairments could be used as the basis for a developed sociology of the absurd. While this sociological sub-category was first proposed by Lyman and Scott in 1970, it is an area of analysis that has received little further attention. Founded upon an assumption of the meaninglessness of life, the sociology of the absurd examines the way in which arbitrary meaning is created and imposed through social interaction. The statement made by Mary's partner Donald, that disabled people see the world 'at its most stupid' (1.3:447ff.) suggests that, as well as being theoretically novel, further research in this area could be socially relevant.

Developing affirming language

The way we use language is an important part of the way that together we construct shared understandings and expectations about people and the way we relate to people. It became clear at the self-advocacy meeting I attended with Roshni that there is a need for action research into the development of new words and concepts in Asian languages such as Punjabi and Urdu so that impairment can be increasingly spoken about and experienced without oppression.

References

- Access 4 U 2 (2009) *Terminology*. [Online]
<http://www.access4u2.com/disabilityawarenesstraining.html>. Accessed 18.03.09
- Althusser, L. (2008) *On Ideology*. London: Verso.
- Archer, M.S. (2003) *Structure, Agency and the Internal Conversation*. Cambridge: Cambridge University Press.
- Arditi, B. and Valentine, J. (1999) *Polemicization: The contingency of the commonplace*. Edinburgh: Edinburgh University Press.
- Aspis, S. (1999) 'What they don't tell disabled people with learning difficulties' in Corker, M. and French, S. *Disability Discourse*. Buckingham: Open University Press
- Atkinson, R. and Flint, J. (2001) 'Accessing Hidden and Hard-to-Reach Populations: Snowball Research Strategies'. *Social Research Update* Issue 33 Summer 2001. University of Surrey. <http://sry.surrey.ac.uk/SRU33.html>. Accessed 17.07.09
- Avery, D. (1999) 'Talking "tragedy": identity issues in the parental story of disability'. In Corker, M. and French, S. (eds.) *Disability Discourse*. Buckingham: Open University Press
- Ballard, K. and McDonald, T. (1999) Disability, Inclusion and Exclusion: Some Insider Accounts and Interpretations. In Ballard, K. (Ed.) *Inclusive Education: International Voices on Disability and Justice*. London: Falmer Press
- Barking and Dagenham.gov.uk (2010) *Positive About Disability: The Two Ticks Symbol*. [Online] <http://www.barking-dagenham.gov.uk/7-hr/two-ticks/two-ticks-menu.html>. Accessed 26.02.10
- Barnes, C. (1994) *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation*. London: Hurst and Co. in association with BCODP
- Barnes, C. (1994) 'Images of disability'. In French, S. (Ed.) *On Equal Terms*. London: Butterworth-Heinemann.
- Barnes, C. (1996) 'Visual impairment and disability'. In Hales, G. (Ed.) *Beyond Disability: Towards an Enabling Society*. London: Sage
- Barnes, C. (1997) 'A Legacy of Oppression: A history of disability in western culture' in Barton, L. and Oliver, M. (Eds.) *Disability Studies: Past, Present and Future*. The Disability Press: Leeds
- Barnes, C. and Mercer, G. (Eds.) (1997) *Doing Disability Research*. Leeds: The Disability Press
- Barnes, C. Mercer, G. and Shakespeare, T. (1998) *Exploring Disability: A Sociological Introduction*. Polity: Cambridge

- Barnes, C. (2004) 'Reflections on Doing Emancipatory Research' in Swain, J. French, S. Barnes, C. and Thomas, C. (Eds.) *Disabling Barriers: Enabling Environments*. London: Sage
- Barnes, M. (1997) *Care, Communities and Citizens*. London: Longman.
- Barton, E.L. (2001) 'Textual Practices of Erasure: Representations of Disability and the Founding of the United Way'. In Wilson, J.C. and Lewiecki-Wilson, C. (Eds.) *Embodied Rhetorics: Disability in Language and Culture*. Carbondale, IL: Southern Illinois University Press.
- Baudrillard, J. (1981) *For a Critique of the Political Economy of the Sign*. New York, NY: Telos Press
- Bauman, Z. (2001) *Thinking Sociologically*. Oxford: Wiley-Blackwell
- Bauman, Z. (2006) *Identity*. Cambridge: Polity
- BBC (2005) *Beyond Boundaries Goes to Africa*. [Online]
www.bbc.co.uk/pressoffice/pressreleases/stories/2005/.../boundaries.shtml.
 Accessed 29.11.09
- BBC (2009) *Beyond Boundaries: Where Are They Now?* [Online]
http://www.bbc.co.uk/blogs/ouch/2009/03/beyond_boundaries_where_are_th.html.
 Accessed 29.11.09
- Becker, H.S. (1991) *Outsiders: Studies in the Sociology of Deviance*. New York, NY: Free Press.
- Beresford, P. (2008) 'A progressive or reactionary challenge? Review Symposium: Disability Rights and Wrongs'. *Disability and Society*, Vol. 21. No. 2. Pp. 217-224
- Blaxter, L. Hughes, C. and Tight, M. (1998) *How To Research*. Buckingham: Open University Press.
- Bourdieu, P. (1990) *The Logic of Practice*. Cambridge: Polity.
- Bourdieu, P. (1998) *On Television*. New York: New Press.
- Bourdieu, P. and Wacquant, L.J.D. (2007) *An Invitation to Reflexive Sociology*. Cambridge: Polity
- Bowler, E. (2009) 'Disabled talent starts to break through'. *Broadcast Now*. [Online]
<http://www.broadcastnow.co.uk/printPage.html?pageid=1961010> Accessed 20.01.09
- Bowman, P. (2008) *Deconstructing Popular Culture*. London: Palgrave Macmillan
- Britt, L. and Heise, D. (2000) 'From Shame to Pride in Identity Politics'. Stryker, S., Owens, T.J. and White, R.W. (Eds.) *Self, Identity and Social Movements*. Minneapolis, MN: University of Minnesota Press.

- Burchardt, T. (2005) *The education and employment of disabled young people*. [Online] <http://www.jrf.org.uk/publications/education-and-employment-disabled-young-people> Accessed 09.09.09
- Burton, G. (2005) *Media and Society: Critical Perspectives*. Maidenhead: Open University Press.
- Butler, J. (1990) *Gender Trouble: Feminism and the Subversion of Identity*. London: Routledge.
- Cameron, C. and Hussey, J. (1981) *A Tale of Christmas Cheer*. High Wycombe: Self-published.
- Cameron, C. (2006) *Better*.
<http://www.raggededgemagazine.com/departments/fiction/000740.html>. Accessed 09.06.09
- Cameron, C. (2007) 'Whose Problem? Disability narratives and available identities'. *Community Development Journal*. Vol 42 No 4 October 2007 pp.501-511.
- Cameron, C. (2008) 'Further towards an affirmation model'. In Campbell, T. Fontes, F. Hemingway, L. Soorenian, A. and Till, C. (Eds.) *Disability Studies: Emerging Insights and Perspectives*. Leeds: The Disability Press
- Cameron, C. (2009) 'Tragic but brave or just crips with chips? Songs and their lyrics in the Disability Arts Movement in Britain'. *Popular Music*. Vol. 28/3. Pp. 381-396
- Campbell, J. and Oliver, M. (1996) *Disability Politics: understanding our past, changing our future*. London: Routledge.
- Campbell, J. (2006) *Assisted Dying: A Matter of Life or Death for Disabled People?*
<http://www.livingwithdignity.info/main/papers/RADAR/euthanasia.pdf> Accessed 19.03.09
- Campbell, J. (2006) *Assisted Dying: A question of choice?* <http://www.leeds.ac.uk/disability-studies/archiveuk/Campbell/Leeds%20Uni%2015%20Nov%202006.pdf>. Accessed 23.03.09
- Capability Scotland (2010) *Collection Boxes*. [Online] <http://www.capability-scotland.org.uk/collectionboxes.aspx>. Accessed 28.02.2010
- Certeau, M. de (1997) *The Practice of Everyday Life*. Berkeley, CA: University of California Press
- Chambers, I. (1993) *Popular Culture: The Cosmopolitan Experience*. London: Routledge
- Charlesworth, S.J. (2000) *A phenomenology of working class experience*. Cambridge: Cambridge University Press.
- Chouliaraki, L. and Fairclough, N. (2005) *Discourse in Late Modernity*. Edinburgh: Edinburgh University Press.

- Cole, J.S. and Johnson, M. (1994) 'Time to Grow Up'. In Shaw, B. (Ed.) *The Ragged Edge: The disability experience from the pages of the first fifteen years of The Disability Rag*. Louisville, KY: Advocado Press
- Collins, A. (2003) *Where Did It All Go Right? Growing up normal in the 70s*. London: Ebury Press
- Corker, M. and Shakespeare, T. (eds.) (2002) *Disability/Postmodernity: Embodiment and Disability Theory*. London: Continuum.
- Corsaro, W. (1997) *The Sociology of Childhood*. London: Sage
- Creswell, J.W. (2007) *Qualitative Enquiry and Research Design: Choosing Among Five Approaches*. London: Sage.
- Crow, L. (1996) 'Including All Our Lives: Renewing the Social Model of Disability' in Morris, J. (Ed.) *Encounters with Strangers: Feminism and Disability*. The Women's Press. London
- Cumberbatch, G. and Negrine, R. (1992) *Images of Disability on Television*. London: Routledge
- Darke, P. (1998) 'Understanding Cinematic Representations of Disability'. In Shakespeare, T. (Ed.) *The Disability Reader: Social Science Perspectives*. London: Cassell
- Davis, L.J. (1995) *Enforcing Normalcy: Disability, deafness and the body*. London: Verso
- Deal, M. (2003) 'Disabled People's Attitudes toward Other Impairment Groups: a hierarchy of impairments'. *Disability and Society*. Vol. 18, No. 7. Pp.897-910
- Debord, G. (1990) *Society of the Spectacle*. London: Rebel Press.
- Dill, K.E. (2009) *How Fantasy Becomes Reality: Seeing through media influence*. Oxford: Oxford University Press
- Drake, R.F. (1999) *Understanding Disability Policies*. London: Macmillan
- Duncombe, S. (2007) *Dream: Re-Imagining Progressive Politics in an Age of Fantasy*. New York, NY: New Press.
- Dyer, R. (2003) *Heavenly Bodies: Film Stars and Society*. London: Routledge.
- Edgate.com (2004) *Paralympics*. [Online]
<http://www2.edgate.com/summergames/paralympics>. Accessed 01.12.09
- Edwards, S.D. (2005) *Disability: Definitions, value and identity* Abingdon: Radcliffe.
- Elias, N. and Scotson, J.L. (1994) *The Established and the Outsiders*. London: Sage.
- Elias, N. (1998) 'On the Concept of Everyday Life'. In Goudsblom, J. and Mennell, S. (Eds.) *The Norbert Elias Reader*. Oxford: Blackwell

- Elias, N. (2000) *The Civilising Process*. Oxford: Blackwell.
- Elias, N. (2001) *The Society of Individuals*. London: Continuum.
- Employers Forum on Disability (2009) *Reasonable adjustments in employment*. [Online] <http://www.e fd.org.uk/employment/reasonable-adjustments>. Accessed 25.09.09
- Esterberg, K.G. (2002) *Qualitative Methods in Social Research*. Maidenhead: McGraw-Hill.
- Farmer, B. (2003) 'The Politics of Everyday Life'. Martin, F. (Ed.) *Interpreting Everyday Culture*. London: Arnold.
- Farmer, B. (2003b) 'The Ideologies of Everyday Life'. In Martin, F. (Ed.) *Interpreting Everyday Culture*. London: Arnold.
- Ferguson, H. (2006) *Phenomenological Sociology: Experience and Insight in Modern Society*. London: Sage.
- Finch, J. (1983) "'It's great to have someone to talk to": the ethics and politics of interviewing women'. In Bell, C. and Roberts, H. (Eds.) *Social Researching: Politics, Problems and Practice*. London: Routledge and Kegan Paul.
- Finger, A. (1994) '...And the Greatest of These is Charity'. In Shaw, B. (Ed.) *The Ragged Edge: The disability experience from the pages of the first fifteen years of The Disability Rag*. Louisville, KY: Advocado Press
- Fiske, J. (1993) *Power Plays: Power Works*. London: Verso.
- Fiske, J. (1995) *Understanding Popular Culture*. London: Routledge
- Foucault, M. (1987) *Discipline and Punish*. London: Penguin.
- Foucault, M. (1998) *The History of Sexuality Vol. 1: The Will to Know* London: Penguin
- Frank, A. (1997) *The Wounded Storyteller: Body, Illness and Ethics*. London: University of Chicago Press
- Fraser, M. (2004) <http://disabilityarts.com/archive/features/mattfraser>. Accessed 30.01.07
- Fraser, N. and Honneth, A. (2003) *Redistribution or Recognition?* London: Verso.
- French, S. (1994) 'The disabled role'. In French, S. (Ed.) *On Equal Terms: Working with disabled people*. London: Butterworth-Heinemann
- Friere, P. (1974) *Pedagogy of the Oppressed*. London: Penguin
- Fromm, E. (2001) *The Fear of Freedom*. London: Routledge.
- Garfinkel, H. (2008) *Studies in Ethnomethodology*. Cambridge: Polity Press
- Goffman, E. (1968) *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin.

- Goffman, E. (1976) *The Presentation of Self in Everyday Life*. London: Penguin
- Giddens, A. (2003) *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Cambridge: Polity.
- Gramsci, A. (1996) *Selections from the Prison Notebooks*. London: Lawrence and Wishart Ltd.
- Guardian.co.uk (2008) *Sex uncovered poll: Education and ethnicity*. [Online]
<http://www.guardian.co.uk/lifeandstyle/2008/oct/26/observer-sex-poll-20082>. Accessed 02.10.09
- Hambrook, C. (2009) *Discussion: Colin Cameron – Further Towards an Affirmative Model of Disability*. [Online]
http://www.disabilityartsonline.org.uk/?item=1125&itemoffset=1&unique_name=affirmative-model-of-disability. Accessed 12.01.10
- Hamer, R. (2009) *Disabled people have the right to access the world* [Online].
<http://news.scotsman.com/opinion/Richard-Hamer-Disabled-people-have.4963192.jp>
 Accessed 19.03.09
- Hardin, M. and Hardin, B. (2008) 'Elite Wheelchair Athletes Relate to Sport Media'. In Gilbert, K. And Schantz, O.J. (eds.) *The Paralympic Games: Empowerment or Side Show?* Maidenhead: Meyer and Meyer
- Harvey, L. (1990) *Critical Social Research*. London: Unwin Hyman
- Hoggart, R. (2005) *Mass Media in a Mass Society: Myth and Reality*. London: Continuum
- Hughes, B. (2005) 'What Can a Foucauldian Analysis Contribute to Disability Theory?' In Tremain, S. (Ed.) *Foucault and the Government of Disability*. Ann Arbor, MI: University of Michigan Press
- Hughes, B. (2007) 'Being Disabled: towards a critical social ontology for disability studies'. In *Disability and Society*. Vol. 22, no. 7
- Hyatt, G.W. (2008) *Resuming my Misbehaving Woman Role*.
<http://www.doitmyselfblog.com/2008/resuming-my-misbehaving-woman-role/> Accessed 15.06.09
- Illich, I. (1996) *The Right to Useful Unemployment and its Professional Enemies*. London: Marion Boyers
- Internet Movie Database (2005) *Footprints in the Snow*. Plot Summary. [Online]
<http://www.imdb.com/title/tt0452622/plotsummary>. Accessed 03.12.09
- Johnson, M. (2003:124) *Make Them Go Away: Clint Eastwood, Christopher Reeve and the case against disability rights*. Advocado Press. Louisville, KY
- Kierkegaard, S. (1978) *Parables of Kierkegaard*. Princeton, NJ: Princeton University Press

- Klages, M. (1999) *Woeful Afflictions: Disability and Sentimentality in Victorian America*. Philadelphia, PA: University of Pennsylvania Press
- Klobas, L. (1988) *Disability Drama in Television and Film*. Jefferson, NC: McFarland and Co.
- Kusenbach, M. (2003) 'Street Phenomenology: The Go-Along as Ethnographic Research Tool'. *Ethnography*.2003:4 [Online] <<http://eth.sagepub.com/cgi/content/abstract/4/3/455>>. Accessed 20.08.2009
- Lefebvre, H. (2008) *Critique of Everyday Life: Vol. I*. London: Verso.
- Levin, J. (1996) *Sociological Snapshots: Seeing Social Structure and Change in Everyday Life*. Thousand Oaks, CA: Pine Forge Press
- Linton, S. (1998) *Claiming Disability: Knowledge and Identity*. New York, NY: New York University Press
- Lodziak, C. (1986) *The Power of Television: A Critical Appraisal*. London: Frances Pinter
- Lodziak, C. (2002) *The Myth of Consumerism*. London: Pluto Press.
- Lofland, J. Snow, D. Anderson, L. Lofland, L.H. (2006) *Analysing Social Settings: A Guide to Qualitative Observation and Analysis, 4th Ed.* London: Thomson Learning.
- Longhurst, B. (2007) *Cultural Change and Ordinary Life*. Maidenhead: Open University Press.
- Lupton, D. (1998) *The Emotional Self*. London: Sage
- Lyman, S.M. and Scott, M.B. (1970) *A Sociology of the Absurd*. New York, NY: Appleton-Century-Crofts
- Markell, P. (2003) *Bound by Recognition*. Princeton, NJ: Princeton University Press
- Marks, D. (1999) *Disability: Controversial Debates and Psychosocial Perspectives*. London: Routledge
- McAdams, D.P. (1993) *The Stories We Live By: Personal Myths and the Making of the Self*. New York, NY: Guilford Press.
- McKnight, J. (2005) 'Professionalised Service and Disabling Help' in Illich, I. Zola, I.K. McKnight, J. Caplan, J. and Shaiken, H. *Disabling Professions*. London: Marion Boyars.
- Merleau-Ponty, M. (2008) *Phenomenology of Perception*. London: Routledge
- Michalko, R. and Titchkosky, T. (2001) 'Putting Disability in its Place: It's Not a Joking Matter'. In Wilson, J.C. Lewiecki-Wilson, C. (Eds.) *Embodied Rhetorics: Disability in Language and Culture*. Carbondale, IL: Southern Illinois University Press.
- Michalko, R. (2002) *The difference that disability makes*. Philadelphia, PA: Temple University Press

- Miller, T. and McHoul, A. (1998) *Popular Culture and Everyday Life*. London: Sage
- Mitchell, D.T. and Snyder, S.L. (2000) *Narrative Prosthesis: Disability and the Dependencies of Difference*. Ann Arbor: The University of Michigan Press
- Montgomery, C. (2006) 'Little Acts of Degradation: Regged Edge Online launches Project Cleigh'. *Ragged Edge Online*. [Online]
<http://www.raggededgemagazine.com/departments/closerlook/00713.html>. Accessed 21.07.2009
- Moore, M. Beazley, S. & Maelzer, J. (1998) *Researching Disability Issues*. Buckingham: Open University Press.
- Moran, J. (2005) *Reading The Everyday*. London: Routledge
- Morris, J. (1993) *Pride Against Prejudice*. London: The Women's Press
- Moustakas, C. (1994) *Phenomenological Research Methods*. London: Sage.
- Murphy, J.W. (2005:161) 'Social Norms and their implications for disability' in Murphy, J.W. and Pardeck, J.T. (Eds.) *Disability Issues for Social Workers and Human Service Professionals in the 21st Century*. New York, NY: Haworth
- Nettleton, S. (1998) *The Sociology of Health and Illness*. Cambridge: Polity Press
- Noble, G. (2003) 'Everyday Work'. In Martin, F. (Ed.) *Interpreting Everyday Culture*. London. Arnold
- Oliver, M. (1990) *The Politics of Disablement*. London: Macmillan.
- Oliver, M. (1996) *Understanding Disability: From Theory to Practice*. London: Macmillan
- Oliver, M. and Barnes, C. (1998) *Disabled People and Social Policy* London: Longman.
- Oliver, M. (2004) 'The social model in action: if I had a hammer'. In Barnes, C. and Mercer, G. (Eds.) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press
- Oliver, M. and Barnes, C. (2006) 'Disability Politics and the Disability Movement in Britain.' [Online]
<http://www.leeds.ac.uk/disability.../Coalition%disability%20politics%20paper.pdf>. Accessed 26.10.09
- Ouellette, L. and Hay, J. (2008) *Better Living Through Reality TV*. Oxford: Blackwell.
- Outsiders (2009) *Outsiders Club* [Online] <http://www.outsiders.org.uk/club>. Accessed 05.10.2009
- Palmer, G. (2003) *Discipline and Liberty: Television and governance* Manchester: Manchester University Press. Manchester

- Paralympics.com (2004) *Paralympian Athlete Profiles*. [Online] http://www.paralympics.com/athlete_profiles/paralympians.htm. Accessed 01.12.09
- Plummer, K. (1997) *Telling Sexual Stories: Power, Change and Social Worlds*. London: Routledge.
- Porter, E.H. (2003) *Pollyanna*. London: Puffin
- Postman, N. (2006) *Amusing Ourselves to Death: Public Discourse in the Age of Show Business*. London: Penguin
- Priestley, M. (1997) 'Whose Research? A personal audit' in Barnes, C. and Mercer, G. (eds.) *Doing Disability Research*. Leeds: The Disability Press
- Priestley, M. (1999) *Disability Politics and Community Care*. London: Jessica Kingsley
- Priestley, M. (2003) *Disability: A Life Course Approach*. Cambridge: Polity Press
- Radway, J. (1987) *Reading the Romance*. London: Verso
- Read, H. (2002) *To Hell with Culture*. London: Routledge
- Read, J. (2000) *Disability, the Family and Society: Listening to mothers*. Buckingham: Open University Press
- Reay, C. (2009) 'Schoolkids need lessons in disability'. In *Disability Now*, September 2009. [Online] <http://www.disabilitynow.org.uk/latest-news2/schoolkids-need-lessons-in-disability> Accessed 23.09.09
- Reeve, D. (2004) 'Psycho-Emotional Dimensions of Disability and the Social Model'. In Barnes, C. and Mercer, G. (eds.) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press
- Reeve, D. (2006) 'Towards a Psychology of Disability: The Emotional Effects of Living in a Disabling Society'. In Goodley, D. and Lawthorn, R. *Disability and Psychology: Critical Introductions and Reflections*. Basingstoke: Palgrave Macmillan
- Rickell, A. (2009) 'Our Movement Needs Leaders'. *Disability Now*. January 2009
- Rieser, R. and Mason, M. (1992) *Disability Equality in the Classroom*. London: Disability Equality in Education. London.
- Rieser, R. (2002) *Disabling Imagery: A teaching guide to disability and moving image* London. BFI/Disability Equality in Education
- Riley, C.A. (2005) *Disability and the Media: Prescriptions for Change*. Hanover, NE: University Press of New England
- Rodriguez, N. And Ryave, A. (2002) *Systematic Self-Observation*. London: Sage.

- Rose, D. (2006) *Better dead than blind*
http://www.bbc.co.uk/ouch/opinion/better_dead_than_blind.shtml. Accessed 23.03.09
- RNIB (2009) *History of RNIB* [online]
<http://www.rnib.org.uk/aboutus/historyofrnib/Pages/rnibhistory.aspxmedia>. Accessed 27.10.09
- Schmitt, R. (2003) *Alienation and Freedom*. Oxford: Worldview Press
- Scott-Hill, M. (2004) 'Impairment, Difference and 'Identity''. In Swain, J. French, S. Barnes, C. and Thomas, C. (Eds.) *Disabling Barriers – Enabling Environments*. 2nd Ed. London: Sage
- Schutz, A. (1970) *On Phenomenology and Social Relations*. Chicago, IL: University of Chicago Press.
- Schutz, A. (1997) *The Phenomenology of the Social World*. Evanston, IL Northwestern University Press.
- Scope (2007) 'See the person not the disability – the Campaign Continues'. In *Horizon, Issue 88, June 2007*. [Online] www.scopevic.org.au Accessed 22.09.09
- Scotsman Newspaper (2009) 'Blind charity aims to raise awareness of visual impairment with tour' [Online]<http://news.scotsman.com/health/Blind-charity-aims-to-raise.5768501.jp>. Accessed 27.10.09
- Shakespeare, T. Gillespie-Sells, K. And Davies, D. (1996) *The Sexual Politics of Disability*. London: Cassell.
- Shakespeare, T. (1997) 'Cultural Representation of Disabled People: dustbins for disavowal'. In Barton, L. and Oliver, M. (Eds.) *Disability Studies: Past, Present and Future*. Leeds: The Disability Press.
- Shakespeare, T. (2000) *Help*. Birmingham: Venture Press
- Shakespeare, T. (2006) *Disability Rights and Wrongs*. Routledge. London
- Shader, K. (2008) *Oblivion*. Hartlepool: self-published
- Shader, K. (2008) *That's The Way*. Hartlepool: self-published
- Shove, E. (2003) *Comfort, Cleanliness and Convenience: The Social Organisation of Normality*. Oxford: Berg
- Sigman, A. (2007) *Remotely Controlled: How television is damaging our lives*. London: Vermilion
- Silverstone, R. (1999) *Television and Everyday Life*. London: Routledge.
- Stebbins, R.A. (2001) *Exploratory Research in the Social Sciences*. London: Sage.
- Stevens, S. (2008) 'Paralympics: I'm no fan'. *Community Care*. 16.10.08

- Stevens, S. (2008) 'Movement Doesn't Move Me'. *Community Care*. 13.11.08
- Stevens, S. (2009) 'Just how disabled am I?' *Community Care*. 27.08.09.
- Stewart, K. (2007) *Ordinary Affects*. Durham, NC: Duke University Press
- Storey, J. (2003) *Cultural Studies and the Study of Popular Culture*. Edinburgh: Edinburgh University Press.
- Stothers, W.G. (2009) 'I Hate Tiny Tim'. In Baird, R.M., Rosenbaum, S.E. and Toombs, S.K. (Eds.) *Disability: The social, political and ethical debate*. New York, NY: Prometheus
- Strauss, A. (2008) *Mirrors and Masks: the Search for Identity* New Brunswick, NJ: Transaction.
- Stryker, S. (2002) *Symbolic Interactionism: a Social Structural Version*. Caldwell, NJ: Blackburn Press.
- Sutherland, A. (2004) *What is Disability Arts?* <http://www.disabilityarts.com/dao/what-is-disarts>. Accessed 30.11.07
- Sutherland, A. (2009) *Chronology of Disability Arts* [Online] http://www.disabilityartsonline.org/?location_id=343. Accessed 22.02.10
- Swain, J. and Lawrence, P. (1994) 'Learning about disability: changing attitudes or challenging understanding?' in French, S. (Ed.) *On Equal Terms: Working with Disabled People*. London: Butterworth-Heinemann
- Swain, J. and French, S. (1998) 'Normality and Disabling Care'. In Brechin, A. Walmsley, J. Katz, J. and Peace, S. (Eds.) *Care Matters: Concepts, Practice and Research in Health and Social Care*. London: Sage
- Swain, J. and Cameron, C. (1999) 'Unless Otherwise Stated: discourses of labelling and identity in coming out'. In Corker, M. and French, S. (Eds.) *Disability Discourse*. Buckingham: Open University Press
- Swain, J. and French, S. (2000) 'Towards an Affirmation Model'. *Disability and Society* 15(4) 569-582.
- Swain, J. French, S. and Cameron, C. (2003) *Controversial Issues in a Disabling Society*. Buckingham: Open University Press
- Swain, J. and French, S. (2008) *Disability On Equal Terms*. London: Sage
- Taylor, P. and Harris, J.Ll. (2008) *Critical Theories of Mass Media: Then and Now*. Maidenhead: Open University Press.
- Thomas, C. (1999) *Female Forms: Experiencing and understanding disability*. Buckingham: Open University Press

- Thomas, C. (2002) 'Disability Theory: Key Ideas, Issues and Thinkers' in Barnes, L. Oliver, M. and Barton, L. (Eds.) *Disability Studies Today*. Cambridge: Polity.
- Thompson, N. (1998) *Promoting Equality: Challenging discrimination and oppression in the human services*. London: Macmillan.
- Thomson, R.G. (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* New York, NY: Columbia University Press
- Titchkosky, T. (2003) *Disability, Self and Society*. Toronto: University of Toronto Press
- Titchkosky, T. (2007) *Reading and Writing Disability Differently: the Textured Life of Embodiment*. Toronto: University of Toronto Press.
- Tollifson, J. (1997) 'Imperfection is a Beautiful Thing: On Disability and Meditation'. In Fries, K. (Ed.) *Staring Back: The Disability Experience From the Inside Out*. New York, NY: Plume.
- Tregaskis, C. (2004) *Constructions of Disability: Researching the interface between disabled and non-disabled people*. London: Routledge
- Turkle, S. (2007) *Evocative Objects: Things We Think With*. Cambridge, MA: Massachusetts Institute of Technology Press
- Turner, G. (2006) *Understanding Celebrity*. London: Sage
- Union of the Physically Impaired Against Segregation (1976) *Fundamental Principles of Disability*. London: UPIAS.
- Van Manen, M. (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. New York, NY: State University of New York Press
- Vernon, A. (1997) 'Reflexivity: The dilemmas of researching from the inside' in Barnes, C. and Mercer, G. *Doing Disability Research*. Leeds: The Disability Press
- Vernon, A. and Swain, J. (2002) 'Theorising Divisions and Hierarchies: Towards a Commonality or Diversity'. In Barnes, C. Oliver, M. and Barton, L. (Eds.) *Disability Studies Today*. Cambridge: Polity
- Watson, N. (2002) 'Well, I know this is going to sound very strange to you, but I don't consider myself as a disabled person: identity and disability'. *Disability and Society*. 17 (5), 509-529
- Watson, N. (2004) 'The Dialectics of Disability: a social model for the 21st century?' In Barnes, C. & Mercer, G. (Eds.) *Implementing the Social Model of Disability: Theory & Research*. Leeds: The Disability Press
- Weedon, C. (2004) *Identity and Culture: Narratives of Difference and Belonging*. Maidenhead: Open University Press
- Willis, S. (1991) *A Primer For Everyday Life*. London: Routledge

Wilson, T. (1995) *Watching Television: Hermeneutics, Reception and Popular Culture*. Cambridge: Polity

Wood, R. (1989) *Care of Disabled People*. [Online]
<http://www.psi.org.uk/publications/archivepdfs/Disability%20and%20social/WOOD.pdf>.
Accessed 16.11.09

World Health Organisation (1981) *International Classification of Impairments, Disabilities and Handicaps*. Geneva: WHO

Wright Mills, C. (1967) *The Sociological Imagination*. Oxford: Oxford University Press

Young, I. M. (1990) *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press

Yue, A. (2003) 'Shopping'. In Martin, F. (Ed.) *Interpreting Everyday Culture*. London: Arnold

Zola, I.K. (2005) 'Healthism and Disabling Medicalization' in Illich, I. Zola, I.K. McKnight, J. Caplan, J. and Shaiken, H. *Disabling Professions*. London: Marion Boyars

Appendix A: Introductory Letter

Participants Sought For PhD Research into Disability Identity Colin Cameron, School of Media, Communication & Sociology, Queen Margaret University, Edinburgh

I am a disabled PhD researcher at Queen Margaret University, Edinburgh. I am currently looking for 10-12 disabled people (anywhere in Britain) who would be interested in taking part in a series of interviews on disability identity. This would involve talking about ways that people think about themselves, experiences that have led them to think the way they do, messages about being disabled they have been given as members of families, communities, society.

I would like to involve:

- people who have really strong & positive disability identities, maybe activists involved in campaigning activity in the disabled people's movement;
- people for whom being disabled is just a fact of life, something to get on with, but not really something to go on about;
- people who really hate being disabled & who can't see anything good in the experience

Participants would each be asked to take part in three interviews in a series of different situations reflecting different parts of their lives. Interviews will be fairly informal, organised loosely around the themes 'Who am I?' & 'How do I fit into the world?'

The social model of disability – the view that people are disabled by physical & social barriers rather than by their own impairments - will be the underlying principle upon which this research is based. Interviews will be carried out between October 2007 & October 2008.

If you are interested in finding out more about this research – either because you would like to be involved as a participant or because you would like to pass information to someone you know who might be interested - please contact:

Colin Cameron
PhD Research Student
School of Media, Communication & Sociology
Queen Margaret University
Corstorphine
Edinburgh EH12 8TS

Email: ccameron@qmu.ac.uk Tel: 01368 864548

Full confidentiality is guaranteed. This research has ethical approval from Queen Margaret University.

Appendix B: Email Extracts

I have reproduced here extracts from a number of emails I received as initial responses to my request for research participants. I have chosen these as examples of the types of responses I received and in terms of the categories into which I placed them. These categories were identified in terms of ways in which respondents described themselves as relating to the experience of being disabled (really positive; just getting on with it; identify negatively; a bit of all three). Unless permission has been given by people to use real names, all personal and place names are disguised.

Really positive

I have received an email from Pam Deepdale at uni in Brum regarding your research.

This is a field I am really interested in from the perspective of autistic advocacy, and the identity politics of the disability movement in the UK, that I have also identified with

(Ben, selected)

I have just read an article in the Xchange Network magazine regarding your proposed research.

I am a 67 year old disabled male who campaigns for the rights of the disabled, as secretary of the Lowlands Coalition of Disabled People and a Director of the Lowlands Council of Voluntary Service I am in contact with my fellow disabled almost on a daily basis

(Arthur, not selected)

Just getting on with it

As per the attached short Bio, I guess I fall into the category of 'just getting on with it', or possibly slightly into the activist camp...

In 1986, Derek competed in his first major disabled competition – a six nations waterski event in Sweden. He went on from there to participate in almost every European and World Championships until retiring in 2003. His main events were slalom and jump and he held numerous world records in both events, and amassed over two dozen gold medals for individual and team placement at European and World championships...

(Derek, not selected)

I myself have a progressive condition and as such recognised under the DDA. My condition means I will be taking medication for life, but the medication does enable me to enjoy day to day living as a non disabled person

(Hazel, selected)

I would be most interested in taking part in your research. I am 42 years old and have progressive MS. I work part-time as an information office. I am married and have one son who like his father is hearing impaired. I believe I have a 'just get on with it' attitude to my

disability although others about me don't i.e. they seem to get more worried about my MS than I do

(Susan, selected but did not reply to several attempts to contact further)

Identify negatively

I have damage to the surface of my brain caused by an aneurysm resulting in my permanent disability to jump, run, carry heavy weights over sustained periods, affected by bright sunlight when viewed from a poorly lit room, blood pressure problems, stage 3 chronic kidney disease, polycystic kidneys, bad leg caused by motorcycle accident aged 20 (am aged 52 now), loss of use of left bicep muscle caused by nerve damage in this accident because of cracked neck, I now have arthritis in my neck making bending and lying in bed quite awkward, top of head hurts at certain times of the day. Yet, despite all this, I appear normal to other people

(Kevin, selected)

I have a adult form of limb girdle muscular dystrophy, although onset was at 13, and diagnosis not until nearly 29... Don't think I have got it figured out yet but would be willing to participate. I would fall into the negative sector of your respondents, and you may have enough of those

(Rose, selected)

A bit of all three

I have a diagnosis of depression, anxiety, and Borderline Personality Disorder... I don't like to think of myself as disabled, but I am beginning to realise that recognising the limitations this sometimes places on me is something I might have to accept to get on with my life. I refuse to be defined by a diagnosis and I get very frustrated by the way it has held me back – either from treatment or just in being at the same point in my life as friends of my age... I have had both negative and positive experiences of being disabled – I guess I don't think of myself as being disabled except for the purpose of filling out forms. But I do see that there are so many little adaptations that could be made that would make society much more inclusive for anyone who is not quite 'normal'

(Helen, selected)

I am a physically disabled man of 43 through a suicide attempt. I also suffer from manic depression. I play guitar, draw portraits, 6 years training at night school in calligraphy. I am very sociable. I volunteer many hours a week. I have been stable many years. Looking forward to getting back to swimming when the kids are back at school. I still walk with limp and a raised shoe, my injuries were serious many broken bones, jaw, leg, foot, minor skull fracture etc. I attend Bonnybank Day Centre in Edinburgh for people with a physical disability every Thursday

(Ash, selected)

I first of all must say that I think I fit into all your categories in one way or another. I became disabled after an accident at work 11 years ago when I was forty years old. I did not feel I was ready to retire just then so after I became involved locally as a volunteer for Red Cross showing other disabled people that life need not stop due to disability you just have to find new interests and ways to get around what stops you from doing the old ones

(Roddy, not selected)

Appendix C: Interview Guide

Does Anybody Like Being Disabled?

Interview Guide

Participant Name:

Interview Date:

Location:

Colin Cameron

PhD Student

School of Media, Communication and Sociology

Queen Margaret University

Edinburgh

August 2007

My signature below is confirmation that I have agreed to take part in a series of interviews with Colin Cameron (School of Media, Communication and Sociology, Queen Margaret University, Edinburgh) as part of his research for his PhD thesis 'Does anybody like being disabled? An exploration of impairment, self and identity in a disabling society'.

The series of interviews will be organised as follows:

- | | |
|--------------|---|
| Interview 1 | This interview will be about establishing my own relationship with disability as an idea or as an identity. Within this interview I will be asked to talk about my own experiences and thoughts on the subject of disability. |
| Interview 2 | This interview will be about my perceptions of media representations of disability and disabled people and about how I view these as resources for disabled people to draw on in addressing questions of identity |
| Interview 3: | This will take place as I carry out an everyday activity identified and agreed between Colin Cameron and myself. In addition to short interviews before and after this activity, I give consent to Colin Cameron's making notes and observations as I carry out this activity in order to develop these into a qualitative description. |

The discussion, comments and observations generated through these interviews will be used by Colin Cameron as data in order to build a thesis exploring tensions for disabled people in the construction of positive personal and social identities within contexts in which self-understanding is shaped both by social structural relations of inequality and unique individual experience.

I agree to be available to take part in these interviews across a period beginning at earliest from summer 2007 and lasting not beyond 2008/2009.

I understand that interviews 1 and 2 are anticipated to take between one and two hours to complete. Interview 3 may take longer depending on the everyday activity identified (although it may also take considerably less time).

I am happy about the reasons why I have been selected as a participant in this research process. Colin Cameron has outlined to me why he has selected me as somebody who can make what he regards as an important and distinctive contribution to his discussion.

I am assured that Colin Cameron's interest here relates only to my opinions and personal experiences. I understand that I do not have to worry about whether what I have to say fits in with what other people think or do.

Colin Cameron has indicated that he will give me the opportunity to confirm or disagree with transcriptions of my interviews/descriptions of my everyday activity and that it is my right, if I wish, to amend or remove any statements or remarks from either transcript or description, or to ask for changes to be made. I agree that I will acknowledge and reply, either confirming or suggesting any changes, when transcripts have been sent.

Assurance has been given me that, unless I have specified otherwise, my personal identity shall not be disclosed within any part of Colin Cameron's written dissertation or in conversation between Colin Cameron and other parties.

It has been made clear to me that I am free, if I wish, at any time during interviews or observation, to interrupt, to ask for clarification, to object to a line of questioning, or finish the interview. Also it is my right if I choose at any time during the interview period to withdraw from the process. If I choose to withdraw it is understood that Colin Cameron will no longer be able to use any data produced through my involvement as part of his research findings.

Colin Cameron has explained that, as an activist and researcher in the disabled people's movement, he is committed to producing this research as emancipatory research, and that this process should be identified as part of the struggle of disabled people for social justice and recognition.

I have given Colin Cameron permission to record the interviews he carries out with me.

Participant's authorisation:

Colin Cameron has discussed the above points with me. I have been given assurance as regards all data produced through this interview. I give my consent to this data being used as part of this research project.

Signed:

Date:

Appendix D: Themes arising from the first series of interviews, produced through open and focussed coding

1. Segregated schooling and its impact
2. Isolation
3. “I am an individual”
4. Sex and relationships
5. Experiencing pity and unwanted attention
6. “I don’t see myself as a disabled person”
7. People who ‘get it’
8. People who don’t ‘get it’
9. Disabled people’s movement or disability movement?
10. “Okay about being who I am”
11. I knew I had health problems, but I didn’t think of that as a disability
12. Hidden impairment and being judged
13. Pain and impairment effects
14. “You don’t have to see yourself as disabled if you don’t want to”
15. Identifying as disabled purely a practical thing
16. “Just don’t talk about it, please”
17. Passing and the emotional costs involved in performing
18. Political identity as disabled
19. Accepting other people’s definitions
20. “It’d be easier if you’d just accept you’re disabled”
21. “Things are getting better”
22. Being disabled is not all one unremitting crap experience
23. The Affirmative Model
24. Disabled people just weren’t seen/ or just were there/ or were seen begging
25. Relief at being diagnosed/ being given description

26. Identity
27. Disability was about other people, but it wasn't about us
28. Disabled people were people in wheelchairs or who had Down's Syndrome
29. The need to 'prove yourself'
30. The Social Model
31. "If I could find a cure..."
32. Charity collecting boxes
33. Disabled people seen as contaminating
34. Does anybody like being disabled?
35. Non-disabled people
36. Oppressed disabled people
37. "I felt grateful for the fact that I was born healthy"
38. Feeling awkward around disabled people
39. They didn't talk about disability at special school
40. "Should I mention about being disabled?"
41. Put off by charities
42. All other health issues seen as related to impairment

Through focussed coding I narrowed these down into eleven refined themes, as also listed:

1. Segregation and its impact
2. Isolation
3. Sex and relationships
4. Experiencing pity and unwanted attention
5. "I don't see myself as a disabled person"
6. Disabled people's movement or disability movement?
7. The Affirmative Model
8. Hidden impairment, passing and being judged
9. Pain and impairment effects

10. Political identity as disabled
- 11 Marks of Oppression

Published Material

Cameron, C. (2007) 'Breve storia del movimento delle persone disabili nel Regno Unito'. *Rivista Sperimentale di Freniatria*. Vol. CXXXI N.2/2007 pp.83-99

Cameron, C. (2007) 'Whose Problem? Disability narratives and available identities'. *Community Development Journal*. Vol 42 No 4 October 2007 pp.501-511.

Cameron, C. (2008) 'Further towards an affirmation model'. In Campbell, T. Fontes, F. Hemingway, L. Soorenian, A. and Till, C. (Eds.) *Disability Studies: Emerging Insights and Perspectives*. Leeds: The Disability Press

Cameron, C. (2009) 'Tragic but brave or just crips with chips? Songs and their lyrics in the Disability Arts Movement in Britain'. *Popular Music*. Vol. 28/3. Pp. 381-396